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ABSTRACT

The report focuses on the National Asscciation of State Mental Retardation Program Directors' project to produce an indepth analysis of income maintenance for the developmentally disabled. The following issues were considered: the disability determination process; eligibility for rehabilitation services; incentives and disincentives to employment; the relationship between living arrangements and benefit levels; and the role and function of the representative payee. Among recommendations for each issue (which are summarized in an initial section) are that: the Social Security Administration (SSA) should issue clear, definitive standards for evaluating non-exertional as well as exertional limitations; the Department of Health, Education, and Welfare should strengthen procedures for identifying and referring Supplemental Security Income (SSI) childhood recipients to appropriate service programs by delegating case finding and referral responsibilities to the local SSA District Office rather than to the state Disability Determination Service; Congress should permit SSA to deduct job-related expenses in determining whether non-blind, disabled individuals under 65 years, are entitled to receive SSI benefits; Congress should conduct an in-depth analysis of present federal policies for financing long term care for the disabled; and SSA should strengthen its efforts to identify and recruit non-institutional representative payees, such as parents, guardians, friends, and advocates. Included are a table of SSI payment levels for disabled persons, by state and by living arrangement, July, 1976; excerpts from letters of endorsement; and tables, charts, and graphs with statistical data from the project. (SBH)

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INCOME MAINTENANCE AND THE DEVELOPMENTALLY DISABLED

An Analysis of Policy Issues

by

Robert M. Gettings
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December, 1977

This paper was developed as part of the NASMRPD project "The Provision of Technical Assistance on Federal Programs of Significance to the Developmentally Disabled", Grant #54-P-71156-3-02, which is supported by the Office of Human Development Services of the U.S. Department of Health, Education, and Welfare

National Association of State Mental Retardation Program Directors, Inc.

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ENDORSEMENTS

The recommendations contained in this report have been endorsed by the following national organizations interested in the welfare of developmentally disabled individuals:

National Association for Retarded Citizens, Inc.

National Association of Private Residential Facilities for the Mentally Retarded, Inc.

National Society for Autistic Children, Inc.

National Easter Seal Society for Crippled Children and Adults, Inc.

Epilepsy Foundation of America, Inc.

United Cerebral Palsy Associations, Inc.

National Association of State Mental Retardation Program Directors, Inc.

Appendix B contains excerpts from the letters of endorsement received from the above organizations.

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TABLE OF CONTENTS

Page

Endorsements iii

Acknowledgements xi

Forward xiii

Table of Contents vii

Summary of Recommendations xv

Chapter I: Purpose and Methodology 1
1. Need for the Study 1
2. General Project Goals and Objectives 1
3. Underlying Assumptions 2
4. Methodology 3
5. Specific Project Objectives in the Area of Income Maintenance 3
6. Action Strategies Related to Income Maintenance 4

Chapter II: Income Maintenance and Developmentally Disabled Persons: An Overview 7
1. Historical Perspective 7
2. Relevant Trends in Federal Financing 8
3. General Forces Influencing Social Security and SSI Policies 11
- Actuarial Deficits in the Social Security Trust Funds 11
- Growth in the Number of Disabled SSI and SSDI Recipients 11
- The Impact of SSI Implementation 12
- The Relationship of Federal Income Maintenance Programs to Other Federal/State Health and Social Services Benefits 13

Chapter III: Disability Determination 17
1. Definition of Disability 17
2. Specific Impairments Related to the Developmentally Disabled 17
- Mental Retardation 17
- Autism 18
- Epilepsy 19
- Cerebral Palsy 19
3. Criteria for Childhood Disability Determinations 19
4. Non-Medical Criteria 20
5. The Disability Determination Process and Quality Control 21

Chapter IV: Eligibility for Rehabilitation Services 27
1. Rehabilitation Services for Adults 27
- Benefit Termination vs. Rehabilitation: A Conflict in Federal Goals 27
- Procedures for Referral to Rehabilitation Services 28
- Interstate Differences in Referral Rates 29
- Low Rate of Acceptances by Vocational Rehabilitation Agencies 30
2. Rehabilitation Services for Children 33
- Referral of SSI Children for Services 34
- Coordination of Services 34
- Individual Service Plans 35
- Provision of Services 35

Chapter V: Incentives and Disincentives to Employment 37
1. The Developmentally Disabled and the Disabled Worker 37
2. The Paradox of Work Incentives for Developmentally Disabled Individuals 39
3. Income Disregards and Benefit Reductions 40

Page

4. The Disincentive Effect of Cumulative Benefits 41
5. The Trial Work Period 41
6. Plan for Achieving Self Support 41
7. Work Related and Living Expenses 43
8. Sheltered Workshop Earnings 43

Chapter VI: The Relationship Between Living Arrangements and Benefit Levels 47
1. The Impact of State Supplementation 47
2. The Interaction of Financial Assistance Programs 50
3. Deeming Parental Income 51
4. The One Third Reduction Rule 51
5. Student Status 52
6. Living Alone vs. Marriage 53
7. Payments to Institutionalized Individuals 53

Chapter VII: The Role and Functions of the Representative Payee 57
1. Determination of Incapacity 57
2. The Selection of a Representative Payee 57
3. Preferential Selection of Institutions over Relatives 58
4. Duties of the Representative Payee 59
   - Use of Benefits 59
   - Disbursement for Current Support and Maintenance 59
   - Disbursements for Personal Needs 59
   - Support of Dependents 59
   - Savings 59
5. Post Selection Policies 59
6. The Performance of Institutional Payees 60
   - Personal Spending 60
   - Group Purchases 61
   - Reporting Responsibilities 61
   - Payment for Care and Maintenance 61
   - Update of Onsite Review Reports 61
7. The Performance of Non-Institutional Representative Payees 61

Appendix A: SSI Payment Levels for Disabled Persons, by State and by Living Arrangement, July, 1976 64

Appendix B: Excerpts from Letters of Endorsement 72

TABLES

Table I-1 - Estimated Expenditures on Developmentally Disabled Persons from Funds Authorized Under Selected Titles of the Social Security Act, FY 1976 2

Table II-1 - Trends in HEW Outlays for Mental Retardation 9

Table II-2 - Developmentally Disabled Beneficiaries of Social Security and Supplemental Security Income Benefits 9

Table IV-1 - State Agency SSI Vocational Rehabilitation Referrals for Week Ending, March, 1977, Rank Ordered by State and Region 31

Table VI-1 - Administration of State Supplementary Benefits, as of October, 1976 48

Page

CHARTS AND GRAPHS

Figure II-1 - Growth in HEW Outlays for Mental Retardation 10

Figure III-1 - States Ranked by Number of Adult Disabled SSI Recipients per 100,000 Population (1975-76) 22

Figure III-2 - States Ranked by the Number of Children Who are Disabled SSI Recipients, per 100,000 Population (1975-76) 23

Figure IV-1 - Screening Table 30

Figure V-1 - Relationship Between Earnings and Benefits Under SSI Program 42

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The Project Staff was assisted in the preparation of this report by many individuals, government agencies, and private associations. Special mention should be made of the guidance and direction provided by members of the Project Advisory Board who helped to sharpen our focus on the relevant issues in income maintenance, avoid numerous errors, and shape the eventual recommendations. Assistance in clarifying current policies and programs in relation to the developmentally disabled was provided by the staff of the Social Security Administration, and particularly Eleanor Bader, who opened countless doors for us within the agency. And finally, for their timeless efforts, a special thanks to Sandra Nicol and Joan Pate who served as project secretaries during the development of the report.

R.M.G.
H.T.
M.W.

FORWARD

This report has been prepared as part of a technical assistance project supported by the Developmental Disabilities Office, Office of Human Development Services, Department of Health, Education, and Welfare (OHD Grant No. 54-P-71156/3). One of the project's major objectives is to demonstrate how consumer, provider and professional interest groups can work together to eliminate barriers to the effective utilization of federal generic assistance programs on behalf of one of society's most vulnerable groups—developmentally disabled citizens. For this reason, every effort has been made to involve representatives of key national organizations in the identification of relevant issues and the formulation of recommendations. A ten member Project Advisory Board has been the main vehicle for achieving consensus among the groups (see membership roster, p. v).

One immediate outgrowth of this approach is that the organizations listed on page iii have seen fit to formally endorse the recommendations contained in this report. This collaborative effort represents a major step forward in our attempts to present a common front on meeting the unique needs of developmentally disabled persons who are entitled to receive federal income maintenance payments. However, the reader should recognize that responsibility for the accuracy of the reported data and the interpretation which is given to the findings rests solely with the authors.

Today, the Nation is engaged in a fundamental reassessment of the federal/state welfare and Social Security systems. Due to financial and time constraints and the complexity of the issues involved, it has not been possible, within the context of this study, to deal with all of the general questions and proposals now under consideration. Instead, the project staff chose to explore the ramifications of a limited range of policy issues which have special relevance to developmentally disabled recipients of Social Security and SSI benefits.

Likewise, the report makes no attempt to comment on the Administration's plans for reforming the current federal/state welfare system, announced by President Carter on August 6, 1977, as this report was in the final stages of development. Although the Carter plan has significant implications for aged, blind, and disabled persons, an overall review suggests that many of the issues raised in the report concerning the operation of the SSI program will be equally applicable to the unified federal cash assistance approach proposed by the Administration.

As Congress undertakes its analysis of welfare reform and Social Security legislation, it is our hope that the report will assist public policymakers and interested citizens to grasp the impact of federal income maintenance expenditures on developmentally disabled citizens.

SUMMARY OF RECOMMENDATIONS

I. DISABILITY DETERMINATION (Chapter III)

- **The Social Security Administration should revise its present criteria for evaluating mentally retarded Supplemental Security Income and Social Security Disability Insurance applicants by incorporating instructions for measuring adaptive behavior.** In this regard, detailed criteria for assessing a claimant's adaptive behavior for purposes of SSI and Social Security eligibility should be developed in cooperation with HEW's Developmental Disabilities Office, the American Association on Mental Deficiency and other interested professional and consumer organizations. (p. 18)

- **SSA should amend Parts A and B of the current evaluation criteria to include a distinctive sub-category on autism under Sections 12 and 112 (Mental and Emotional Disorders).** Until a complete technical definition is developed, we urge SSA to adopt the National Society for Autistic Children's short definition of autism. (p. 19).

- **The Social Security Administration should issue clear, definitive standards for evaluating non-exertional as well as exertional limitations.** (p. 21)

- **In order to reduce the error rate in disability determinations, SSA's quality assurance program should be expanded.** In addition, the review process should be extended to all types of SSI case actions, including denials and periodic redeterminations. (p. 21)

- **SSA should discontinue the use of standardized denial notices and improve procedures for informing claimants of the specific reasons for the denial of benefits.** Provision also should be made for a face-to-face meeting between the claimant and an SSA representative when a denial appeal is filed. (p. 21)

- **The wide variations between states in per capita enrollments of children and adults in the SSI program should be analyzed to determine whether there is inconsistent and inequitable application of the current federal test of disability. Congress should mandate that SSA complete such an in-depth analysis and report its findings at the earliest possible date.** (p. 24)

II. ELIGIBILITY FOR REHABILITATION SERVICES (Chapter IV)

- **The goals and objectives of federally funded rehabilitation programs for the disabled under the Rehabilitation Act of 1973 and the SSDI and SSI Beneficiary Rehabilitation Programs should be more closely coordinated in order to give an increased number of severely disabled persons access to needed services.** (p. 28)

- **Congress and HEW should strengthen the role of state VR agencies in the rehabilitation of SSDI and SSI recipients by authorizing the use of Title II and Title XVI funds for rehabilitation services leading to increased earnings and a consequent reduction of benefits** (p. 28)

- **Congress should require SSA, in cooperation with the Rehabilitation Services Administration, to complete an in-depth analysis of the reasons for the wide variations between states in the rates of referral and acceptance of children and adults for rehabilitation services.** Policies should be issued by the two agencies to insure interstate consistency in the referral process. (p. 33)

- **The Department of Health, Education, and Welfare should strengthen procedures for identifying and referring SSI childhood recipients to appropriate service programs by delegating case finding and referral**

responsibilities to the local SSA District Office rather than to the state Disability Determination Service. In addition, the practice of out-stationing state/county welfare personnel in Social Security District offices and other attempts to establish closer working relations between the federal SSI and state welfare systems should be encouraged. (p. 34)

- **DHEW should fund a series of model statewide and areawide projects to demonstrate more effective methods for insuring that SSI eligible children who are referred for services actually receive the services they need in the proper sequence and appropriate degree of intensity.** (p. 34)

- **Congress should mandate that the federal offices administering individualized program planning requirements work together to eliminate duplication, conflict, and confusion surrounding the responsibility for carrying out this function.** The Secretary of Health, Education, and Welfare should appoint an intra-departmental task force to address these issues. (p. 35)

III. INCENTIVES AND DISINCENTIVES TO EMPLOYMENT (Chapter V)

- **Congress should mandate a major collaborative longitudinal study of the effects of Social Security and SSI benefits on the work behavior of various categories of disabled recipients including those who are developmentally disabled, to determine the most appropriate means of assisting individuals who are capable of entering or re-entering the labor market.** Such a study should be undertaken jointly by the Departments of Labor and Health, Education, and Welfare and should examine both the incentives and disincentives to entry into the work force by the disabled individual. (p. 38)

- **The feasibility and need for a separate, identifiable program of benefits for adults disabled in childhood—including a special set of work incentives—should be examined by Congress.** (p. 38)

- **Any legislative efforts to restrict the eligibility of younger disabled workers, or to limit payments to this group, should not be applied to adult recipients of SSI or Social Security benefits who were disabled in childhood.** (p. 39)

- **The 24-month "second waiting period" for Medicare payments should be eliminated for Social Security beneficiaries disabled in childhood.** (p. 39)

- **Congress should eliminate the substantial gainful activity test of disability from the Act and, in its place, use the same earnings limitation and benefit reduction formula applied to aged and blind recipients of SSI.** (p. 39)

- **The duration of the trial work period should be extended to 24 months, and a time period should be established within which the entire trial work period must take place or else be recycled to zero.** (p. 41)

- **The Social Security Administration should revise its current policies governing plans for achieving self-support to allow SSI and SSDI recipients to establish legitimate pre-vocational objectives.** (p. 43)

- **Congress should permit SSA to deduct job-related expenses in determining whether non-blind, disabled individuals, under 65 years of age, are entitled to receive SSI benefits.** (p. 43)

- **Congress should authorize an additional monthly increment for blind and disabled SSI recipients who require in-home assistance (i.e., attendent services or social supervision).** The amount of this additional payment should be based on the level or intensity of the individual's need for such services. (p. 43)

- **Congress and SSA officials should work cooperatively to assure that the legitimate earnings of sheltered workshop clients are treated as earned income for purposes of determining SSI eligibility and the level of monthly benefits. (p. 44)**

IV. THE RELATIONSHIP BETWEEN LIVING ARRANGEMENTS AND BENEFIT LEVELS (Chapter VI)

- **Congress should carefully review the purposes and structure of state supplemental payments to determine the most equitable and effective approaches to assisting disabled persons to live in the least restrictive living environment compatible with their needs and personal preferences.** The goal should be to strike a reasonable balance between administrative efficiency and appropriately meeting the needs of disabled Americans. (p. 50)

- **The Social Security Administration should promulgate regulations governing the treatment of state or local payments based on need which exclude all forms of assistance furnished to SSI recipients on the basis of economic and social need by a state and local government. In addition, Congress should enact into law the language of Section 111 of the House-passed version of H.R. 7200 which would require SSA to exclude from countable income any contribution made by a non-profit organization on behalf of an SSI recipient living in a non-institutional setting.** (p. 51)

- **Congress should repeal Section 1612(a)(2)(A)(i) of the Social Security Act which mandates a one-third reduction in federal payments to any recipient living in the household of another.** (p. 52)

- **Congress should enact legislation to lower the statutory age of majority from 21 to 18.** (p. 53)

- **Married couples, both of whom are entitled to SSI benefits, should be treated as two eligible individuals for payment purposes.** (p. 53)

- **Congress should conduct an in-depth analysis of present federal policies for financing long term care for the disabled.** Included in this review should be the way in which Medicaid, SSI, Social Security and Social Services interact to provide incentives and disincentives to long term institutionalization. (p. 54)

- **All SSI recipients residing in institutional settings—both public and privately operated facilities—should be entitled to receive a monthly personal needs allowance at least equal to the current payment to recipients in Medicaid eligible facilities (presently $25 per month).** (p. 54)

V. THE ROLE AND FUNCTIONS OF THE REPRESENTATIVE PAYEE (Chapter VII)

- **SSA should strengthen its efforts to identify and recruit non-institutional representative payees, such as parents, guardians, friends, advocates.** (p. 58)

- **SSA's on-site review program should be extended to private, non-profit and proprietary facilities acting as representative payees for Title II and Title XVI beneficiaries.** (p. 60)

- **The Social Security Administration should provide policy and procedural guidelines for individuals and institutions that serve as representative payees.** The guidelines for institutions should contain suggested methods of accounting for residents' funds, informing the staff about funds available to residents, and methods for reaching decisions about expenditures for care and maintenance, personal needs and savings. (p. 61)

- **The Commissioner of Social Security should appoint a joint study group made up of regional and district office staff with responsibility for on-site reviews, and public institutional officials who serve as representative payees, to identify ways of improving the quality of information generated through the on-site review process and thereby to increase the usefulness and accuracy of these reports to SSA, the institution, the beneficiary and client advocacy agencies.** (p. 61)

- **SSA's auditing and reporting responsibilities as they affect non-institutional representative payees should be strengthened.** (p. 62)

CHAPTER I

PURPOSE AND METHODOLOGY

1. NEED FOR THE STUDY. Perhaps the most noteworthy trend in financing services to developmentally disabled individuals over the past two decades has been the rapid expansion in federal assistance for residential and community-based programs. By far the largest proportion of this increase has come, not through the familiar categorical grant programs, but rather as a result of expanded eligibility for assistance under federal health, social services and welfare programs.

Braddock, in a comprehensive analysis of HEW expenditures for mental retardation activities, reported that the Department's outlays for social insurance and welfare-related payments on behalf of retarded children and adults grew from approximately $75 million in FY 1957 to over $730 million in FY 1973.[2] More recently, Boggs has updated these estimates and found that HEW is currently expending between $2 and $2.3 billion annually on income security and related benefits to developmentally disabled persons, as authorized under the various titles of the Social Security Act.[1] Her estimates of FY 1976 federal expenditures on behalf of developmentally disabled individuals under these programs are summarized in Table I-1 (see p. 2).

Despite the inroads which have been made over the past twenty years, however, developmentally disabled persons do not participate fully in many federally assisted human service programs. While the reasons for their limited involvement in certain federal transportation, food assistance, housing, health, income maintenance, and employment programs are manifold, the general barriers can be classified in the following two major areas: (a) lack of clear, accurate information concerning the benefits which developmentally disabled persons might derive from selected federal programs; and (b) the intentional or unintentional erection of barriers to participation by developmentally disabled persons due to a failure to understand the specialized needs of this target population and lingering misconceptions about their capabilities.

2. GENERAL PROJECT GOALS AND OBJECTIVES. In order to address the problems identified above, the National Association of State Mental Retardation Program Directors, Inc., sought and received grant support from HEW's Developmental Disabilities Office in October, 1976, to: (a) assist the variety of existing national, state and local consumer interest groups and provider organizations concerned with developmentally disabled children and adults to take better advantage of existing federal generic assistance programs; and (b) help federal officials responsible for administering such programs to gain a better understanding of how the goals of their programs intersect with the interests of developmentally disabled persons.

The overarching goals of the project are: (a) to expand the benefits available to developmentally disabled persons through three, carefully selected federal human service program areas; and (b) to demonstrate a conceptual approach to providing technical assistance which will help both consumer advocates and service providers to make better use of generic federal assistance programs.

In pursuit of these goals, the following basic objectives have been established for the project:

- Identify the types and frequency of problems encountered by state and local service providers and advocacy groups in seeking generic federal assistance on behalf of developmentally disabled persons;
- Select three federal program areas for intensive study and complete an indepth analysis of the policy barriers to fuller participation by developmentally disabled persons in each area;
- Study the nature of intra and inter-regional barriers to full utilization of federal generic assistance programs by developmentally disabled persons in three standard federal regional areas;
- Meet with key federal officials at both the central office and regional levels to discuss the impact of selected program policies on the delivery of services to developmentally disabled persons;
- Develop collaborative strategies with other national organizations interested in developmentally disabled persons in a shared effort to broaden the participation of the target population in the selected federal program areas;

TABLE I-1

Estimated Expenditure on Developmentally Disabled Persons from Funds Authorized Under Selected Titles of the Social Security Act, FY 1976.

(In Thousands of Dollars)

Program	Statutory Authority	Est. FY 1976 Expenditures
Disability Insurance	Title II	455,000
Supplemental Security Income	Title XVI	600,000
Medicare	Title XVIII	300,000
Medicaid	Title XIX	517,000
Social Services	Title XX	300,000
Total		2,172,000

Source: Boggs, E. M., "Income Maintenance: Federal Income Resources for Persons with Long Term Disabilities Originating in Childhood" in *Mental Retardation and Other Developmental Disabilities*, Vol. IX, Joseph Wortis (editor): Brunner/Mazel, New Yor, N.Y.: 1977, pp. 251-273.

- Develop audio-visual presentations which will illustrate to key federal officials how the programmatic needs of developmentally disabled persons intersect with the goals of the target federal programs;
- Assist national consumer and professional groups interested in developmentally disabled persons—and their state and local affiliates—to make better use of federal generic assistance programs.

3. UNDERLYING ASSUMPTIONS. In most instances, the multi-billion dollar human resource programs offering the greatest potential for expanding services to developmentally disabled individuals have a bewildering array of legislative objectives, administrative regulations and policies and application procedures which appear impenetrable to the neophyte applicant. Many of the frustrations associated with obtaining such support often can be traced to the difficulty in getting information which clearly spells out the relevant benefits available to developmentally disabled persons and precise procedures for accessing such support. The combination of language barriers and the lack of clearly delineated policies on how the agencies' programs affect developmentally disabled persons often prove to be an insurmountable barrier, even to the most sophisticated service provider or consumer advocate. It takes a major commitment of time and effort to learn the relevant terminology used by the agency, understand its basic operating policies and creatively apply available federal resources to improve services to developmentally disabled individuals. Few service providers and consumer representatives have the time and tenacity necessary to undertake such ventures—especially when the chances of obtaining federal assistance seem problematic from the outset.

One of the fundamental hypotheses underlying the current project is that any attempt to expand the federal health, housing and income maintenance benefits available to developmentally disabled persons must involve an indepth analysis of the operating processes, application procedures and any existing policy barriers to full participation by the target population. For this reason, emphasis has been placed on systematically gathering and analyzing information about selected federal programs, identifying impediments to fuller utilization by developmentally disabled persons and establishing strategies for dealing with such impediments.

A second basic assumption is that more can be accomplished in changing federal policies and practices through the collaborative action of consumer, professional and provider organizations interested in developmentally disabled persons than through the unilateral pursuit of individual organizational goals. Thus, one of the primary operating principles of the project has been to work closely with other organizations affiliated with the Coalition Concerned with Developmental Disabilities in identifying issues and possible action strategies.

Finally, the motivation for the study grows out of two oft-repeated concerns expressed by interested consumers and professionals: (a) that the ways in which government policies are interpreted often vary significantly from one federal regional/area/district office to another; and (b) that it is often difficult to identify the source of barriers to participation by developmentally disabled individuals in particular programs (i.e., intra-state, regional or national policies and/or practices).

4. METHODOLOGY. In order to select the three target areas for intensive study, the project staff began by preparing a "decision paper." The purpose of this paper was to summarize the relevant policy issues surrounding the utilization of various federal programs affecting developmentally disabled persons. The paper was then used as a tool to assist the staff, in consultation with a ten member Project Advisory Board, to select the three program areas for indepth analysis.

The decision paper was divided into eight broad program areas: daytime habilitative services, education, food and nutrition, health, housing, income maintenance, transportation and vocational training and employment. A variety of techniques were employed to identify relevant policy issues in each of the eight program areas, including a review of the relevant literature, interviews with responsible federal officials and knowledgeable consumer representatives, an analysis of legislative and administrative positions taken by concerned national consumer and professional organizations, and a series of structured telephone interviews with a sample of representatives of state and local provider and advocacy groups.

In order to have a conceptional framework within which the impact of generic federal assistance programs could be assessed, the project staff identified four interrelated programmatic trends—deinstitutionalization, normalization, the developmental service model and the individualization of services. Then, specific policy issues in each of the eight program areas were reviewed to determine whether they would impact positively or negatively on these key programmatic trends in the field.

Once all of the above information had been gathered, analyzed and summarized the following selection criteria were developed to assist the staff and the Project Advisory Board to decide, in a reasonably objective fashion, which three of the eight program areas should be selected for indepth study:

- Commonality of Needs. The extent to which the identified problems/issues were common to persons with mental retardation, cerebral palsy, epilepsy and autism.
- Intersecting Programs. The number and types of intersecting federal programs potentially involved in the resolution of the identified problems/issues.
- Timeliness. The likelihood that administrative and/or legislative decisions affecting the resolution of the identified problems/issues would be made within the specified time frame of the project.
- Dollar Impact. The potential dollar value which could be assigned to accessing a particular generic assistance program or eliminating a specific barrier to participation by developmentally disabled persons.
- Decentralized Administration. The likelihood that resolution of a particular set of problems/issues would involve administrative actions at several governmental levels (i.e., central office, regional/area office, state, etc.).
- Impact of non-CCDD Groups. The likelihood that groups other than those associated with the Consortium Concerned with Developmental Disabilities would actively seek to eliminate any identified problems/issues.

Using these selection criteria the Project Advisory Board and the Association's Board of Directors were asked to review the decision paper and rank order the eight program areas. Based on the composite rankings, the following three areas were selected for intensive study: income maintenance, housing and health.

5. SPECIFIC PROJECT OBJECTIVES IN THE AREA OF INCOME MAINTENANCE. Among the factors which led to the selection of income maintenance as one of the target areas for project attention were: (a) the massive federal commitment to income maintenance benefits on behalf of developmentally disabled persons (see Table II-2 p. 9); (b) the keystone role of SSI and Social Security benefits in designing effective and economically viable programming alternatives for the majority of developmentally disabled adults (as well as children from needy families)—especially in community-based settings; (c) the significant number, range and complexity of problems surrounding the optimal and appropriate utilization of federal income maintenance resources (especially SSI) on behalf of developmentally disabled persons; and (d) the current emphasis on welfare reform in the new Administration which could lead to fundamental changes in federal income maintenance programs.

As an initial step toward meeting the project's goals, it was determined that the following areas should be examined in a series of issue papers:

- the relationship between SSI eligibility and receipt of other federal non-cash benefits (medical assistance, social services, food stamps, etc.) and possible solutions to existing inequities and "notch" problems affecting developmentally disabled individuals;
- various issues surrounding the disability determination process used in the Social Security and SSI programs, including the childhood disability criteria, delays in claims processing, and the substantial gainful activity test;
- actual and potential inequities in the SSI income and resources tests, including deeming of parental income and treatment of unearned income received from public and nonpublic agencies;
- problems associated with variations in SSI benefit levels based on the recipient's or potential recipient's place of residence (e.g., application of the one-third reduction rule and other disincentives to living with relatives; the definition of an institution and its ramifications for the development of various types of public, nonprofit and proprietary community living facilities);
- existing procedures for the appointment and monitoring of representative payees under both the Social Security and SSI programs;
- current and proposed work incentives in the Social Security and SSI programs as well as the extent to which such provisions either achieve or fail to achieve their intended purposes (e.g., the effects of the trial work period and the treatment of wages received by sheltered workshop and work activities center clients).

Subsequently, these papers were edited and compiled into the succeeding chapters of this report.

6. ACTION STRATEGIES RELATED TO INCOME MAINTENANCE. Although the issuance of this report marks the culmination of months of hard work, the project staff does not view it as the end point of its analytical efforts in the area of income maintenance. Due to time and financing constraints the staff has been forced to base its findings and recommendations on information and data which, in some instances, was woefully inadequate. Therefore, some of the conclusions which have been drawn are, of necessity, highly tentative and open to debate.

Given the dearth of available literature on the subject, the complexity of the issues involved and the technological limitations of human service policy analysis, it is not surprising that many uncertainties remain. In fact, this very problem was anticipated when the original project application was developed and, as a result, funding was requested and granted for a series of small-scaled follow-up studies.

Before putting the final touches on the present report, the project staff solicited bids for a series of three contractual studies on areas in need of further analysis. A contract was later signed with Human Services Research Institute, Inc., a nonprofit policy research firm based in Washington, D.C., to:

- identify factors associated with the variations among states in rates of enrollment in the SSI program and rates of subsequent acceptance for vocational rehabilitation services.
- identify particular obstacles to the designation of parents, guardians, or friends of SSI and SSDI recipients as representative payees for persons who reside in institutions.
- assess the impact of current SSI policies on the development and utilization of less restrictive living arrangements for developmentally disabled persons.

In addition to reviewing the available literature, conducting a series of mail surveys and interviewing key federal officials, the contractor is responsible for completing site visits to four carefully selected states to determine the nature and extent of problems associated with these three policy areas. Hopefully, the information obtained from these in-depth analyses will permit the project staff and the Advisory Board to develop more precise recommendations and action strategies for addressing any problems which are identified. To assist the reader of this report textual notes have been added to pinpoint areas where information and data from the contractual studies may help to clarify the precise nature or scope of the problems alluded to in this report.

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CHAPTER II

INCOME MAINTENANCE AND THE DEVELOPMENTALLY DISABLED: AN OVERVIEW

I. HISTORICAL PERSPECTIVE. American income maintenance programs began to take their present shape during the two decades preceding World War II. During this period the level of aid to needy individuals varied widely from state to state, but in every case remained low, even during the relatively prosperous years of the 1920's. By 1926, all but six states had "mother aid" programs; by 1933 old age assistance was offered in 25 states. Then, just as state income maintenance programs appeared to be gaining momentum, all such efforts were overwhelmed by the Great Depression.[10]

New Deal economists saw economic paralysis as the central problem of the Depression and believed that "underconsumption and underprivilege were at the root" of the Nation's recurrent economic troubles.[16] Combined with a humanitarian motive, this belief served to produce programs for the relief of individual hardship—especially programs of cash and social assistance for destitute individuals. Thus, the Social Security Act of 1935 was expected, eventually, to put an end to the economic crisis which gripped the country as well as to destitution and underprivilege in the United States. The basic purpose of the legislation was to provide pension income for retired workers, cash assistance for workers during periods of unemployment and, with the 1939 amendments, public assistance for special categories of the needy—the old, the blind, and disabled, dependent children.

The 1956 amendments to the Social Security Act established what is often referred to as the "adult disabled child program." Under this legislation, surviving children of retired, deceased or disabled workers became eligible to receive benefits if they had a permanent disability originating before age 18.

It was originally estimated that there would be approximately 20,000 eligible beneficiaries under this amendment.[6] However, by June, 1977 enrollment in the program had reached 372,000 adults disabled in childhood.[13] In commenting on the impact of the 1956 amendments, Boggs has noted that the extraordinarily high levels of enrollment in the program has demonstrated, as almost no other program could have done, the extent of disability due to mental retardation in the noninstitutionalized adult population.[1]

An analysis of the causes of disability among Title II adult/childhood recipients indicates that the primary diagnosis in 70 percent of the cases is mental retardation.[3,14] Thus, approximately 260,400 Social Security beneficiaries disabled in childhood have mental retardation as their primary disability. In addition, an estimated 10 percent of Title II childhood disability beneficiaries suffer from either cerebral palsy, epilepsy or autism.[3,14]

The Social Security Amendments of 1950 established a separate federal grant-in-aid program to assist states in providing cash benefits to needy disabled adults (18 years or older). This state-administered, federally-assisted program, entitled Aid to the Permanently and Totally Disabled, was intended to help the states meet the needs of individuals who were too disabled to enter the work force. However, because of differences in political outlook and variations in tax bases, the states, over the years, evolved quite distinctive APTD programs. By July 1972, for example, monthly state payments to a blind or disabled individual ranged from $66 in Mississippi to $250 in Alaska.[24] Similarly, the disability criteria and income eligibility standards adopted by the various states varied markedly.

In order to eliminate the interstate inequities associated with the APTD program (and companion programs for the aged and blind) and provide a decent minimum income for adult welfare recipients, Congress, in 1972, added a new title (Title XVI) to the Social Security Act authorizing the Supplemental Security Income program (P.L. 92-603). Besides replacing the state administered adult welfare programs (APTD, OAA and AB) with a new, consolidated federal program, P.L. 92-603 established a single, federal definition of disability which paralleled the Title II definition.

In enacting the Supplemental Security Income program, however, Congress intended to do more than just create a federal version of the old state-run adult welfare programs. As the Senate Finance Committee put it at the time:

> "The Committee bill would make a major departure from the traditional concept of public

assistance as it now applies to the aged, the blind, and the disabled. Building on the present social security program, it would create a new Federal program administered by the Social Security Administration, designed to provide a positive assurance that the Nation's aged, blind, and disabled people would no longer have to subsist on below-poverty-level incomes."[24]

In assigning administrative responsibility to the Social Security Administration, Congress hoped to minimize the stigma of welfare by assuring recipients the dignity, accuracy and efficiency which had long characterized the operation of the Social Security program. The establishment of an initial federal payment standard for individuals of $130 per month* also eliminated the wide disparities in benefit levels which existed under the old APTD program.

At the same time, it was clear that, in most instances, those states with a higher payment standard under the old categorical programs would want to set higher benefit levels under the new SSI program. Consequently, the law permitted states to supplement the federal SSI payment and, if a state so elected, have the Social Security Administration include such supplemental amounts in a single check to the recipient.

In explaining the rationale for this provision, the staff of the Senate Finance Committee recently concluded that,

". . . it appears from the legislative history that the intent was not to give the Social Security Administration a new type of job to do . . . but rather to take the income maintenance functions previously handled by the State welfare agencies and transform them into something which could be handled by the Social Security Administration largely in the way in which it had always handled social security benefits."[26]

2. RELEVANT TRENDS IN FEDERAL FINANCING. Over the past fifteen years, income maintenance payments have constituted the single largest source of HEW outlays for mental retardation activities. Table II-1 illustrates the trends in HEW obligations for income maintenance, related welfare outlay (Medicaid and Social Services), and other forms of service, research and training assistance (see p. 9).

Figure II-1 traces the amount obligated for Social Security benefits and federal public assistance payments on behalf of mentally retarded individuals between FY 1962 and FY 1977 (see p. 10).

In addition to demonstrating the general rise in federal aid over the period, the chart shows the sixfold increase in federal income maintenance expenditures which has taken place in the last six years. Two major reasons for this sharp increase can be cited: (a) implementation of the Supplemental Security Income program, with its generally more liberal federal benefits, in January, 1974; and (b) the sharp increase in SSI and Social Security benefit levels since the automatic cost-of-living provision was added to the Act in 1973.*

Table II-2 summarizes the number of developmentally disabled individuals eligible for benefits under Title II and XVI and the estimated federal outlays for this purpose in FY 1977** (see p. 9).

Despite the rapid growth in SSI and Social Security payments to developmentally disabled persons, this commitment pales when compared to the overall dimensions of the federal government's income maintenance program. In FY 1977 the Social Security Administration expects to pay out over $69 billion in OASI and SSDI benefits plus an additional $5 billion in payments to SSI recipients.

Even if we restrict the discussion to recipients of federal disability benefits, developmentally disabled individuals make up less than 12 percent of the 2.5 million SSDI beneficiaries (less than 7 percent if dependents are considered) and roughly 18 percent of SSI disability recipients. In total, approximately 12 percent of all SSI outlays and 0.7 percent of Social Security payments (or 6 percent if only SSDI payments are considered) are obligated for developmentally disabled recipients.

These facts are important to keep in mind when analyzing the way in which income maintenance policies affect developmentally disabled persons. **The origin of many of**

*Subsequently, Congress authorized an annual cost-of-living increase for all SSI and Social Security recipients (P.L. 93-66). As a result, the federal benefit level for an individual recipient has gradually increased from $130 in 1974 to $177.80 in July, 1977.

*Although comparable figures are not available on expenditures for non-retarded, developmentally disabled persons, there is reason to believe that the overall trend in federal outlays is similar.

**The figures shown in Table II-1 do not take into account the fact that some developmentally disabled recipients are also eligible to receive Title II benefits. As of September, 1976, approximately one-third of all SSI disability recipients were also receiving SSDI benefits averaging $139.55 per month.[26] The percent of developmentally disabled persons who are dual SSI/SSDI beneficiaries can be expected to be considerably lower since such persons normally will not have sufficient earnings credits to qualify for Title II payments on their own work records.

TABLE II-1

Trends in HEW Outlays for Mental Retardation

(in thousands of dollars)

Fiscal Year	Income Maintenance		Welfare Related Benefits	Other Service, Research, Training Grants	Total
	Title II	Public Assistance			
1962	52,000	35,193	–	22,349	109,542
1963	63,000	42,073	1,853	22,781	129,707
1964	64,000	49,017	4,780	40,676	158,473
1965	71,000	55,456	7,209	96,985	230,650
1966	85,000	61,908	9,815	122,852	279,575
1967	94,000	64,933	14,948	155,190	329,071
1968	107,000	74,041	18,358	164,870	364,269
1969	127,000	83,129	111,642	205,041	526,812
1970	143,000	95,670	157,761	237,904	634,335
1971	176,000	124,485	180,733	271,265	752,483
1972	198,205	201,286	302,900	294,538	996,929
1973	240,809	236,639	594,780	305,652	1,377,880
1974	302,551	290,645	562,600	341,229	1,497,025
1975	348,592	403,964	459,247	318,941	1,530,744
1976	403,402	481,920	540,800	309,133	1,735,255
1977 (est.)	478,674	576,953	584,800	326,691	1,967,118

Source: FY 1962–FY 1971 Data from David Braddock: *Mental Retardation Funds, An Analysis of Federal Policy*, (unpublished doctorial dissertation, University of Texas at Austin, 1973). FY 1972–FY 1977 (est.) were compiled by the Office for Handicapped Individuals, Department of Health, Education, and Welfare. (Unpublished data.)

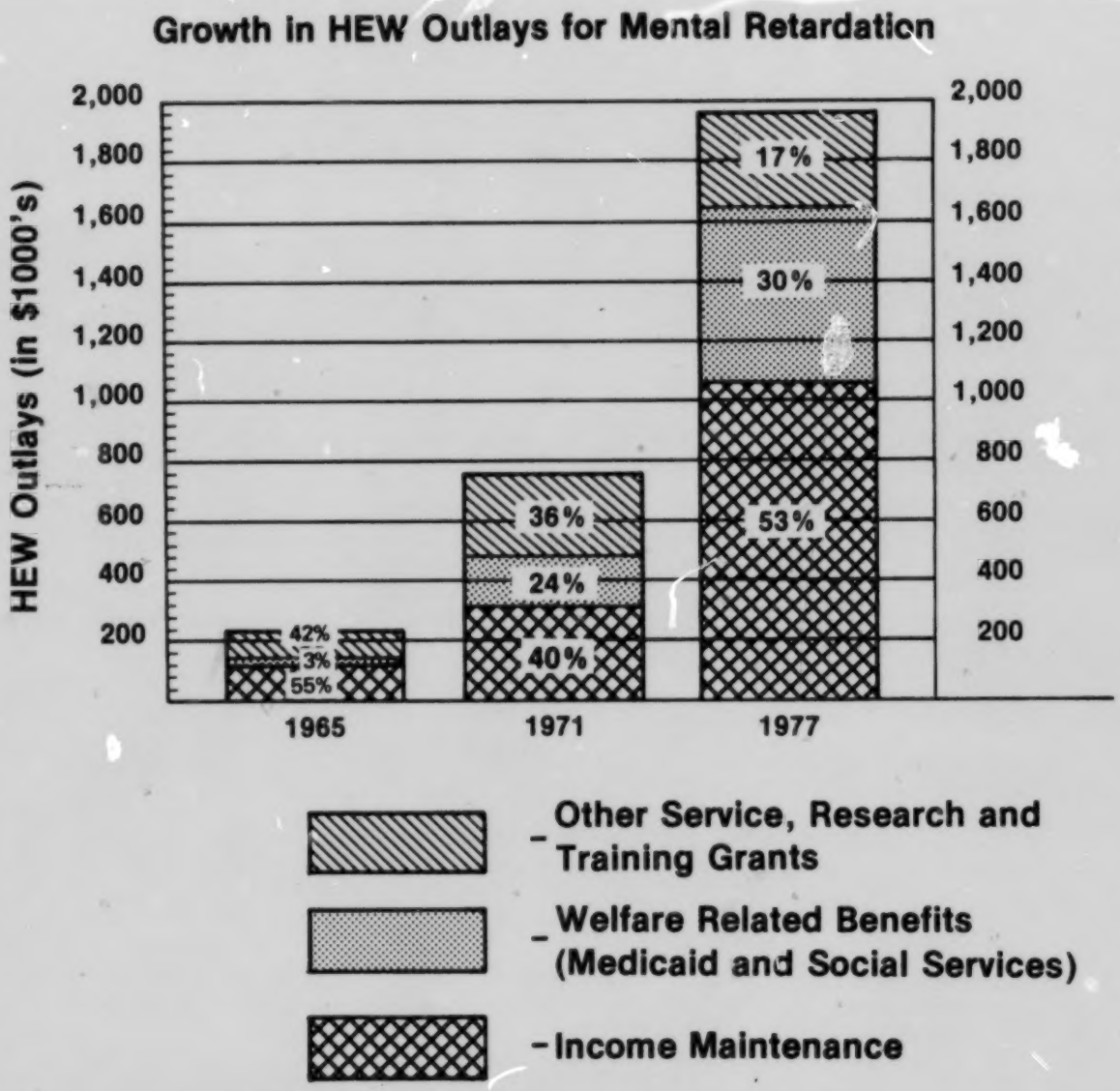
TABLE II-2

Developmentally Disabled Beneficiaries of Social Security and Supplemental Security Income as of December, 1976

Disability	TITLE II		TITLE XVI		Total – TITLE II & TITLE XVI	
	Est. No. of Beneficiaries	Estimated Benefits	Est. No. of Beneficiaries	Estimated Benefits	Est. No. of Beneficiaries	Estimated Benefits
Mental Retardation	280,000	$483,000	370,000	$616,000	650,000	$1,099,000
Cerebral Palsy	25,000	$ 45,500	33,000	$ 55,677	58,000	$ 101,177
Epilepsy	25,000	$ 46,500	40,000	$ 66,117	65,000	$ 112,617
Autism	Not Available	Not Available	Not Available	Not Available	Not Available	Not Available

Source: Social Security Administration, Office of Research and Statistics, Baltimore, Maryland: Unpublished data.

Figure II - 1



FY 1962 - FY 1971 data from David Braddock, *Mental Retardation Funds, An Analysis of Federal Policy* (unpublished doctoral dissertation), University of Texas at Austin, 1973; FY 1972 - FY 1977 data (est.) were compiled by the Office for Handicapped Individuals, Department of Health, Education, and Welfare (unpublished data).

the [illegible] identified in this report is the problem of meeting the unique needs of developmentally disabled persons within the context of the huge Social Security and SSI programs. Statutory and regulatory policies, molded around adults disabled during their prime working years or aged recipients of SSI, occasionally work at cross purposes with the needs of developmentally disabled children and adults. The capability of groups interested in developmentally disabled individuals to influence policies which impact on over 36 million Americans who receive Social Security and SSI benefits is often severely limited.

3. GENERAL FORCES INFLUENCING SOCIAL SECURITY AND SSI POLICIES. Since the succeeding chapters of this report will focus exclusively on the special impact of Social Security and SSI on developmentally disabled persons, it is important that the reader understand some of the general problems facing these massive income transfer programs. Like any other recipient of Social Security and/or SSI benefits, an eligible developmentally disabled individual will be affected by the way in which these problems are addressed. In addition, these overriding, system-wide issues establish the context in which more specialized decisions concerning developmentally disabled persons must be made.

Actuarial Deficits in the Social Security Trust Funds. One of the most pressing problems facing the Social Security Administration is the growing deficits in the Old Age and Survivors Insurance (OASI) and Disability Insurance (DI) trust funds. The 1977 reports of the Board of Trustees of these funds indicate that the OASI program will run out of funds about 1983 while the DI fund will exhaust its reserve in early 1979. These gloomy predictions are in sharp contrast to the Board's 1972 estimates which showed that the program was in exact actuarial balance (i.e., long term income equaled long term outgo).[23]

In reality, the deficits in the Social Security trust funds can be viewed as two sets of interactive problems: (a) a short-term deficit caused by recent economic conditions; and (b) a long term deficit reflecting basic structural changes in the economy and inaccurate actuarial assumptions. The root cause of the short term deficit can be traced to the rapid rise in the Consumer Price Index during the period of 1972 to 1977 coupled with an increase in the taxable wage base which was insufficient to offset the impact of rising prices. Since Congress tied Social Security benefit levels to the CPI in 1973 by authorizing automatic, annual cost-of-living adjustments (P.L. 93-66), the gap between trust fund income and outgo has rapidly widened. This gap was accentuated by the 1974-75 recession, which resulted in an unanticipated decline in Social Security tax collections.

In May of this year, the Carter Administration submitted a series of proposals to restore the actuarial balance in the Social Security trust funds. As this report goes to press, Congress has given its final approval to a Social Security finance package which promises to restore the solvency of the trust funds, at least through the year 2000. It is too early to predict what long range impact the recent financing crisis will have on Congressional and Administration attitudes towards future expansions in benefits. However, many observers are predicting that Congress will look with a more jaundiced eye at costly proposals to broaden benefits—especially after American workers begin to feel the full economic impact of the steep increases in Social Security taxes called for in the new legislation.

Growth in the Number of Disabled SSI and SSDI Recipients. One problem plaguing both the SSDI and SSI programs is the increasing number of disabled persons qualifying for benefits. Between 1967 and 1974 the number of disabled workers receiving SSDI benefits grew from 1.5 to 2.5 million. The Board of Trustees of the Social Security funds has estimated that the number of SSDI beneficiaries will grow to ten million by the year 2001.

The same general pattern of growth is discernible in the Supplemental Security Income program. Initial Administration projections that one of every three SSI recipients would be disabled have proven inaccurate. Instead, as of December, 1976, the proportion of persons receiving benefits on the basis of disability climbed to 48.8 percent (as compared to 41.6 percent in June, 1974).* At the present time, about 80 percent of all SSI applications and 70 percent of new benefit awards are based on disability.** While SSI is generally perceived to be a program primarily for the aged, "in fact, it is rapidly moving in the direction of being a program serving more disabled than aged persons."[26]

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*It also should be noted that the lower-then-anticipated number of aged recipients reflects higher Social Security benefits, improved and expanded private pension plans and a general upturn in the income of elderly individuals and couples.

**As Ozawa and Lindsey have pointed out, the trend toward a higher proportion of disabled recipients began long before the advent of the SSI program. In 1950 the disabled made up only 2.3 percent of the combined OAA, AB and APTD caseloads. By 1973, 40.2 percent of all adult welfare recipients were getting APTD benefits.[11]

Commenting on the projected growth in the SSDI and SSI caseloads, Harvard economist Otto Eckstein, in recent testimony before the Senate Finance Committee, called the current estimates "striking . . . considering the improved health care for the American people."[4] Finance Committee Chairman Russell Long (D.-La.) was more blunt in a recent press conference when he said the SSDI program provides "an incentive for people who are not totally disabled to convince themselves that they are totally disabled in order to receive benefits."[15]

The reasons for this sudden increase in SSI and SSDI disability enrollments are complex and difficult to assess. However, the following are some of the most frequently cited explanations:

- The increasing use of such subjective, non-medical factors as age, education and work experience in determining whether an applicant meets the statutory test of disability;
- A steady decline in the percentage of terminations in benefits (from 3.21 percent in 1967 to 1.07 percent in 1975) due, in large part, to a higher percentage of young workers on the disability rolls who can be expected to have longer periods of eligibility;
- Increased longevity among disabled beneficiaries already on the rolls;
- Disincentives to work which are built into the current test of "substantial gainful activity," plus the limitations on a "trial work period" and a "plan for achieving self-support" (see Chapter V);
- Minimal impact of efforts to rehabilitate disabled Title II and Title XVI recipients (see Chapter IV);
- The high rate of reversals of denied claims (30 percent at the state level and 50 percent at the hearing level) which leads to excessive appeals and possible unequal treatment for individuals who do not file appeals;
- Inadequate control of the quality of disability determinations made at the district office and state agency levels.

In addition to the above explanations which are applicable to both the SSI and SSDI programs, the following specific reasons might be cited for the greater-than-expected growth in the SSI disability caseload:

- The income eligibility test for disability benefits has become substantially less stringent in a significant number of states since implementation of the SSI program, thus, sharply increasing the potential number of eligible persons;
- The SSI definition of disability is less rigid than the test used in a majority of the states under the former state-administered APTD program;
- The SSI program extended coverage to blind and disabled children who were ineligible under the former APTD and AB programs;
- A general increase in the longevity of the age group between 45 and 65 which has tended to have the highest rate of disabled persons.

Because of these and other problems, there appears to be growing support in Congress for modifying the Title II and Title XVI disability programs. The staff of the Senate Finance Committee probably summed up this new attitude when it concluded that: "The findings of . . . studies [and] the observations of the staff indicate that the disability programs are in a general state of disarray."[26] It seems inevitable that these emerging concerns will color Congress' view of any proposals to alter the existing programs in the near future.

The Impact of SSI Implementation. The initial high expectations for the Supplemental Security Income program were based largely on Congressional and public confidence in the Social Security Administration's capacity to assume the administrative task of running a massive new, social welfare program as well as the agency's reputation for efficient and effective management. The new program was viewed by Congress as a logical extension of SSA's mission. In practice, however, the SSI program has suffered from a myraid of legislative and administrative problems which have led to "a much lower than expected quality of administration . . . ."[26]

No attempt will be made in this report to analyze the management difficulties SSA encountered in trying to launch "the largest civilian program ever undertaken by the federal government." Several studies have attempted to disect the implementation problems encountered by SSA, assess what went wrong and recommend corrective actions.[19,20,26] For present purposes it will suffice to point out that inadequacies in computer systems, an insufficient number of thoroughly trained staff, deficient quality controls, and a general underestimation of the complexity of the tasks involved led to an initial administrative crisis which is still not entirely resolved.

Congress, however, must share much of the blame for the early difficulties faced by SSA in attempting to implement the SSI program. Numerous deficiencies and inequities in the program's original statutory authority were discovered during the implementation phase which

led Congress to adopt a whole series of corrective amendments. The confusion and delays associated with these changes were a significant factor in the high initial error rate and lengthy backlog in processing claims.

While SSA has absorbed the initial shock of managing the SSI program, many of the scars remain. Clearly, the agency's image as one of the most efficiently run arms of the federal government has been badly tarnished. As a result, staff morale has been adversely affected which has resulted in the resignation of many key staff members. Loss of such key personnel—some of whom had been with the agency since the Social Security program was launched in 1935—has not only exacerbated the SSI management problems but led to a gradual deterioration in the quality of SSA's other programs (i.e., OASI, SSDI, HI and Black Lung).

Writing for the Washington Post, Hayes Johnson captured the mood of many SSA officials when he noted:

> "In all of its experience, Social Security had dealt only with those who had paid their money into the system through payroll taxes. Those, in other words, who had earned their benefits. Now, picking up the welfare load, they were dealing with the core of the urban poor."[9]

Whether the Social Security Administration will be able to overcome the persistent SSI administrative problems and regain its image as a model of efficient management is still an open question. It seems clear, however, that the frustrations and humiliation this justifiably proud agency has faced over the past few years will be reflected in the general character of agency decision-making in the future.

The Relationship of Federal Income Maintenance Programs to Other Federal/State Health and Social Service Benefits. As indicated earlier, Congress saw the Supplemental Security Income program as a logical extension of SSA's responsibilities under the existing Social Security programs. In other words, the agency's primary role would be to efficiently and accurately administer benefit payments in accordance with statutorily specified criteria. Individualized assistance, such as special needs grants and social and medical services, were to remain the responsibility of the states.[26]

In practice, however, this neat division between federal and state roles proved overly simplistic. Because of the statutory linkages between SSI and a variety of welfare-related benefits (e.g., Medicaid, social services, food stamps and emergency assistance), the Social Security Administration was suddenly plunged into a complex webb of interagency and intergovernmental relationships. This was an unfamiliar role to SSA personnel who previously had been able to operate fairly independently, while still maintaining liaison with other public agencies and outside interest groups.

Since the advent of the SSI program, the Social Security Administration has had to enter into a mind-boggling series of agreements with the states concerning mandatory and optional supplementation, determination of eligibility for Medicaid benefits, disability determinations and the provision of rehabilitation services. The striking variations in these agreements has added immeasurably to the complexity of operating the program (see Chapter IV, V, and VI).

In addition, by assuming responsibility for assisting clients who, unlike the average Social Security beneficiary, generally had much more extensive needs for other human services, SSA inherited the complex task of referring applicants and recipients to appropriate service agencies. This was a task, in retrospect, which the agency was ill-prepared to perform.

In effect then for hundreds of thousands of aged, blind and disabled persons eligibility for SSI benefits became the gateway to a panoply of federal/state welfare benefits. The decision of whether an individual was entitled to benefits became inexorably intertwined with his eligibility for social services, Medicaid, food stamps and other forms of assistance. SSI emerged as the trigger mechanism which would open the door to these other public assistance programs.

Unfortunately for SSA, each related state administered service program retains its own eligibility criteria, administrative structure and operational procedures. When this fact is combined with the incredible state-by-state variations in benefit levels, operating policies and organizational configurations, it is no wonder that the Supplemental Security Income program has been such a gigantic headache to run.

One of the major reasons for the wide variations between adult welfare benefits in the states is the fact that the SSI program is a direct descendant of the old state administered, categorical assistance programs for the aged, blind and disabled. The problems spawned by this historical development are well illustrated in the treatment of SSI eligibility among persons in various forms of institutional care (see Chapter VI).

As the staff of the Senate Finance Committee has pointed out,

> "The wide variety and generally high level of costs for care in institutions do not fit conveniently within the theoretical goal of the Supplemental Security Income program of providing an essentially uniform level of income support. . . ."[26]

In practice, the current law attempts to accommodate,

> "a variety of policies developed over the years under the former State welfare programs, with the result that SSI recipients are treated differently depending upon the types and circumstances of the institutional care being provided."[26]

SSA has been forced to develop a series of hair-splitting policies which have tended to make illogical distinctions between similarly situated recipients. As a result, the capability of states to assure that SSI funds represent a socially desirable investment has been diminished.

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INCOME MAINTENANCE AND THE DEVELOPMENTALLY DISABLED: AN OVERVIEW

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CHAPTER III

DISABILITY DETERMINATION

This study of eligibility for Social Security and SSI disability benefits addresses those issues which are of particular significance to the developmentally disabled population. Certain problem areas are not covered due to their more general applicability and the amount of effort by other concerned groups to influence relevant statutory and administrative policies. Examples of such areas are the controversy over whether or not SSA should use the "average man" concept in specifying vocational evaluation criteria, how claimants should be represented in administrative appeals, SSA's use or misuse of "administrative notice," and the delays in the disability determination process.

1. DEFINITION OF DISABILITY. For purposes of eligibility for Social Security Disability Insurance benefits, disability is defined in Section 223(d)(1)(A) of the Social Security Act as: "An inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than twelve months." The SSI program utilizes the same definition of disability (Section 1614(a)(3) of the Act) except that eligibility is extended to children under eighteen years of age when the child's impairment is of "comparable severity" to that which is disabling to an adult.

The development of medical evidence of disability is a very important step in the process of determining whether an applicant is eligible for Social Security and/or SSI benefits. Medical evidence alone can justify a finding that the individual is not disabled, even when the individual has never engaged in substantial gainful activity.* The medical evaluation criteria, known as the "listing of impairments," specifies the types of evidence that are acceptable as proof of an individual's disability.[12,13] While these listings are not necessarily all inclusive, they do set the parameters for medical evidence. For the most part, they consist of impairments to major body systems—e.g., circulatory system, digestive system, respiratory system, and so forth. The listings require that the severity or level of impairment be established by symptoms, signs, and findings, "which are demonstrable by medically acceptable clinical and laboratory diagnostic techniques."[13] With few exceptions, the evidence must be demonstrated by objective measures, such as intelligence tests, X-ray examination, EEG, and measures of cellular immunity mediators.

The listings are divided into two sections: Part A covers impairments applicable to both children and adults, while Part B focuses exclusively on diseases and conditions unique to childhood.

2. SPECIAL IMPAIRMENTS RELATED TO THE DEVELOPMENTALLY DISABLED.

Mental Retardation: Mental deficiency or mental retardation is defined by the Social Security Administration as: "A lifelong disorder characterized by below-average intellectual endowment as measured by standard intelligence (IQ) tests and associated with impairment in one or more of the following areas: learning, maturation, and social adjustment."[13]

Although this definition permits consideration of the learning, maturation, and social adjustment of an individual, the discussion of evidence required in such cases makes it clear that the degree of impairment should be determined primarily on the basis of IQ tests and the medical report. Section 12-05 of the medical evaluation criteria describes the condition of mental deficiency as being manifested by:

> "A. Severe mental and social incapacity as evidenced by marked dependence upon others for personal needs (e.g., bathing, washing, dressing, etc.) and inability to understand the spoken word and inability to avoid physical danger (fire, cars, etc.) and inability to follow simple directions and inability to read, write, and perform simple calculations; or
> B. IQ of 49 or less; or
> C. IQ of 50 to 69, inclusive and;
> 1. Inability to perform routine, repetitive tasks, or
> 2. A physical or other mental impairment resulting in restriction of function."[12]

*See Chapter V for a discussion of the concept of "substantial gainful activity."

The Social Security Administration's primary reliance on medical evidence about body systems in the determination of impairment fails to reflect current thinking in the field of mental retardation. The term mental retardation, as defined by the American Association on Mental Deficiency (AAMD), requires that an individual demonstrate deficiencies in both adaptive behavior and measured intelligence. This definition was originally developed in 1959[5] and has since been refined on several occasions. The current (1973) definition states that: "Mental Retardation refers to significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior, and manifested during the developmental period."[4]

Despite the adoption of the revised AAMD definition and its widespread acceptance among professionals in the field, SSA still relies heavily on IQ scores to establish the level or severity of an applicant's mental impairment. Little attempt is made to take into account the social and environmental factors which frequently determine whether or not an individual with intellectual or cognitive deficits is able to function successfully in society.

Every person reacts differently to a given level of impairment. Thus, similar impairments may result in different disabling or handicapping conditions. Some persons are more disabled by a given level of impairment than others for reasons other than the impairment itself. Such reasons include motivation, age, education, family cohesiveness, and environmental or attitudinal barriers. In other words, the ability of the individual to cope with his environment—his adaptive behavior—is a critical factor in determining the nature and severity of an impairment.

SSA officials believe that the heavy reliance on IQ tests is justified in terms of the current state of the art in differential diagnosis of mental retardation. They argue that "IQ is much more stable than adaptive behavior and therefore much more suitable for the evaluation of disability."[10] However, as Nagi reminds us:

> The utility of indicators, or criterion factors, depends upon (a) the degree to which they are identifiable, (b) the degree to which they are measurable, and (c) the degree to which their contribution to disability are identifiable and measurable. The problem lies primarily in the third requirement, and, **in this respect, medical factors are just as problematic as those of a non-medical nature** (emphasis added).[17]

It is unnecessary and undesirable to make assumptions about an impairment based predominently on IQ measures or status of body systems. Direct measurement of the type and severity of the handicapping behavior is possible. Over the past decade, a number of behavioral assessment and functional impairment scales have been developed which are helpful in ascertaining the degree to which a retarded individual is capable of adjusting to his social environment. Although the science of behavioral assessment is still in its infancy, numerous standardized scales are now widely used in clinical practice. Such instruments as the Vineland Social Maturity Scales, the AAMD Adaptive Behavior Scales, and the Minnesota Multiphasic Personality Inventory, for example, provide valid and reliable measurements of observable adaptive behavior.

It is important to note that Congress took cognizance of the need for a stronger emphasis on the use of behavioral assessment tools in the Developmentally Disabled Assistance and Bill of Rights Act of 1975, when it directed the Secretary of Health, Education, and Welfare to develop a comprehensive evaluation system which "provides objective measures of the developmental progress of persons with developmental disabilities. . ." (Section 110, P.L. 94-103). Design work on such a system is currently underway, with support from the Developmental Disabilities Office in the Office of Human Development Services.

Recommendation: SSA should revise its present criteria for evaluating mentally retarded SSI and SSDI applicants by incorporating explicit instructions for measuring adaptive behavior. In this regard, detailed criteria for assessing a claimant's adaptive behavior for purposes of SSI and Social Security eligibility should be developed in cooperation with HEW's Developmental Disabilities Office, the American Association on Mental Deficiency and other interested professional and consumer organizations.

Autism: Autism is an identifiable syndrome that occurs in approximately five out of every 10,000 births. It is a severely incapacitating, life-long disability that generally appears during the first three years of life. In recent years, it has been recognized as an identifiable disabling syndrome in federal legislation such as the Developmental Disabilities Act, as amended (P.L. 94-103), and the Education for All Handicapped Children Act (P.L. 94-142).

Autism, however, is not recognized by SSA as a distinctive diagnostic entity in the current listing of

impairments. Under the heading of "functional psychotic disorders" in the adult listing (Section 12.03, Part A) "autistic or other regressive behavior" is cited as one of seven possible manifestations of the condition. Similarly, in the childhood listings (Part B), Section 112.03 (psychosis of infancy and childhood) refers to several possible indicators often associated with autism including significant withdrawal or detachment, impaired sense of reality, bizarre behavior patterns, strong need for maintenance of sameness and panic at threat of separation from parent.

Social Security Administration officials argue that the current evaluation criteria does not define individual diagnoses, but rather major diagnostic groups. The criteria, they contend, provides adequate grounds for declaring an autistic individual disabled, within the meaning of the Title II and Title XVI definitions, where the available medical evidence supports such a finding.

The issue boils down to whether autism is a sufficiently distinctive condition to warrant separate identification in SSA's disability evaluation criteria. Although the authors of this report accept the rationale underlying SSA's current position, we are deeply troubled by the recurring reports that autistic individuals are "falling between the cracks" of the existing diagnostic criteria. Faced with a choice between structural consistency and equitable treatment of disability applicants, we would opt for the latter approach.

Recognition of autism as a unique syndrome within the framework of the present listing of impairments would be consistent with contemporary classifications of mental disorders. It would also protect otherwise qualified individuals from being denied the SSI and Social Security benefits which are due them.

Recommendation: SSA should amend Parts A and B of the current disability evaluation criteria to include a distinctive sub-category on autism under mental and emotional disorders. Until a complete, technical definition is developed, we urge SSA to use the National Society for Autistic Children's short definition of autism as the basis for delineating the clinical manifestations of the disorder. This definition includes the following major symptoms caused by a physical disorder of the brain:

- "Disturbances in the rate of appearance of physical, social and language skills.
- Abnormal responses to sensations. Any one or a combination of sight, hearing, touch, pain, balance, smell, taste, and the way a child holds his body are affected.
- Speech and language are absent or delayed while specific thinking capabilities may be present. Immature rhythms of speech, limited understanding of ideas and the use of words without attaching the usual meaning to them is common.
- Abnormal ways of relating to people and things. They do not respond appropriately to adults and other children. Objects and toys are not used as normally intended."[8]

The omission of autism from the listing of impairments is symptomatic of the general difficulty in improving and updating SSA's official diagnostic manual. For example, it wasn't until the late 1960's that SSA recognized mental deficiency as an umbrella term for a variety of congenital malformations, metabolic disorders, and other causes of severe mental and social incapacity.

Even today, specific learning disabilities is not recognized as a disabling condition by the Social Security Administration, even though the term has been widely used in clinical practice and in accepted diagnostic manuals for at least the past decade. While the vast majority of learning disabled children either outgrow or adjust sufficiently to their handicap so that they would not qualify under the existing Title II/XVI test of disability, most clinicians agree that there is a small but significant percentage of the population who face substantial, lifelong disorders which meet the statutory test of both longevity and severity.

Epilepsy: The criteria for evaluating epileptics can be found in Section 11.00 of the "listing of impairments." The general test of SSI eligibility applicable to this group is that the individual must have experienced major motor seizures occuring more frequently than once a month or minor motor seizures occurring more frequently than once a week, in spite of prescribed treatment.

Cerebral Palsy: Cerebral palsy is considered a disability if it is combined with "an IQ of 69 or less; or abnormal behavior patterns, such as destructiveness or emotional instability; or significant interference in communication due to speech, hearing or visual defect; or moderate motor deficit in two extremities."[12]

3. CRITERIA FOR CHILDHOOD DISABILITY DETERMINATIONS. Revised SSI regulations governing the determination of childhood disability and a special list of diseases and conditions unique to the developmental period were issued by SSA early in 1977.[3]

Although SSA claims to have employed developmental milestones in evaluating childhood disabilities for many

years, these instructions had previously been issued in the form of a disability insurance letter to state agencies, rather than as formalized SSA regulations.

The new "listing of impairments" for children includes criteria specifically addressed to mental retardation, seizure disorder, cerebral palsy, and psychosis of infancy and childhood.

It is permissible to use functional evaluation criteria in suspected cases of mental retardation when a child's age or severity of disability precludes formal intelligence testing. In these cases, the norms to be applied are those developmental milestones which SSA notes will be "found in any widely used standard pediatrics text."[3] In addition, when IQ testing proves feasible, a score of 59 is set as the upper limit for a finding of disability, assuming the child has no associated physical or mental impairments. (N.B., the similar cut-off score for adults is 49, although SSA reportedly has a proposal under consideration to raise this figure to 59.) A child with an IQ between 60 and 69 may also qualify for benefits if he or she is afflicted with another "physical or mental impairment imposing additional and significant restriction of function or developmental progression."[3,13]

The specific criteria for determining SSI eligibility for an epileptic child are slightly modified from those applicable to adults. The child must experience at least one major motor seizure per month despite undergoing at least three months of prescribed treatment. If the condition is combined with mental retardation, an emotional or communicative disorder, a visual defect or adverse effects of medication, a minimum of at least one major motor seizure in the year just prior to application is sufficient grounds for a disability finding.

The criteria for cerebral palsy is that the child must have suffered from persistent motor impairment involving two extremities which, despite prescribed therapy, interferes with daily activities and results in disruption of body movements, gait and posture. Less severe motor dysfunction (but more than a slight manifestation of the disorder) may be considered evidence of a disability, especially if the child's cerebral palsy is combined with mental retardation, epileptic seizures, communication disorders, visual defects or significant emotional problems.

As indicated above, no specific mention of autism is included in the list of childhood conditions. SSA maintains that the condition of autism is covered under the category of psychosis of infancy and childhood (Section 112.03).

4. NON-MEDICAL CRITERIA. As a result of both statutory liberalization of the disability test and a variety of court decisions over the past two decades, factors such as age, education and work experience now play an important role in the determination of disability. However, as Nagi has pointed out, the adoption of a multi-causal model of disability does not necessarily lead to the adoption of a balanced multi-faceted evaluation criteria since "agencies tend to operationalize the definitions around the more readily identifiable indicators or measurable criteria."[7]

The Social Security Administration has come under growing criticism for its failure to issue guidelines on how to evaluate non-medical factors which generally are less subject to objective evaluation than the medical criteria outlined in the listing of impairments. In response to such criticism, both from Congress and consumer groups, late in 1976 SSA developed draft regulations for evaluating non-medical, vocational factors.[15] These rules include specific guidelines for the evaluation of impairments manifested by exertional limitations—i.e., limitation on the claimant's ability to walk, lift and carry heavy objects. However, no comparable criteria was included for determining how non-exertional limitations should be considered in determining an individual's capacity to work.

Developmentally disabled persons generally have numerous work-related handicaps—some of which have no relationship to exertional limitations. Many disabled individuals experience psychological/emotional problems as an integral part of, or as a response to, a physical/mental impairment. For example,

- Autistic individuals often exhibit inappropriate social behaviors which may render them unacceptable for job placement even though they have the physical and cognitive skills necessary to perform the assigned tasks.
- A moderately retarded young man may possess normal or near normal physical capabilities and still lack the mental capacity and/or emotional stability to perform job related tasks.
- Similarly, an epileptic with seizures partially controlled by medication may face insurmountable obstacles to entering the work force because of emotional disorders related to his epilepsy.

Some might argue that there is no place for such highly subjective factors as motivation and emotional state in a program which is supposed to be assessing whether the applicant has a medically determinable disability.

However, it is often impossible to make such determinations without first reviewing the applicant's age, education, motivation, and psychological/emotional response to his or her disability. The question then boils down to whether such judgments are to be based on explicit, written criteria or left entirely to the administrative whim of thousands of individual disability determination workers across the country. Under the circumstances, specific rules for evaluating psychological/emotional factors seem essential.

Recommendation: The Social Security Administration should issue clear, definitive standards for evaluating non-exertional as well as exertional limitations.

5. THE DISABILITY DETERMINATION PROCESS AND QUALITY CONTROL. Determining whether an individual is eligible for SSI and/or SSDI benefits is a highly complex, multi-faceted process. The responsibilities of the SSA district office include taking the application, performing the intake interview, determining if the individual meets the income and resource requirements (for SSI eligibility only) and completing the non-medical case development. All relevant information is then forwarded to the Disability Determination Service (DDS), a state agency working under contract with the Social Security Administration. DDS teams, each comprised of a physician and a disability examiner, develop all medical evidence and prepare the disability determination.

Personnel in the DDS normally do not see the applicant but may contact the applicant by letter or phone in order to obtain additional information or schedule further examinations.

The case review section in the appropriate regional office of the Bureau of Disability Insurance (BDI) reviews sample claims in an effort to assure national consistency. The purpose of this review is to determine whether the philosophy and guidelines of SSA are being followed and not whether there is individual equity.

Statistics from the current sample review procedure in SSI show that one out of every five disability determinations is either wrong or based on insufficient evidence.[19] This high error rate is difficult to justify.

A 1976 study by the General Accounting Office identified a number of problems associated with the present disability determination process. The analysis included an adjudication of the same 221 SSI and Social Security disability claims by each of ten state agencies in six regions. The GAO found that there was "a significant lack of agreement among the ten states on the disposition of the sample claims. Where some states approved a claim, others denied it, and still others said there was insufficient documentation upon which to render a decision."[18]

The sample cases were also adjudicated by SSA's Bureau of Disability Insurance Reviewers. The Agency's own investigative branch agreed with the decisions for only 76 (64%) of the 119 claims on which six or more of the states were in complete agreement.

High error rates may be evidence that the disability criteria are too general, that personnel who apply the criteria are not adequately trained, or that there are other impediments to enrollment in the client processing system. For example, the use of standardized denial notices does not inform claimants of the specific reasons for denial of benefits. In addition, the disability determination process does not provide for a face-to-face meeting when the claimant files an appeal.

Recommendation: In order to reduce the error rate in disability determinations, SSA's quality assurance program should be expanded. Whether or not it is necessary to reinstitute a 100 percent review of all awards or simply expand the current 5 percent sample is a decision which can be made only after carefully reviewing the options available. In any event, the review process should be extended to <u>all</u> types of SSI case actions, including denials and periodic redeterminations.

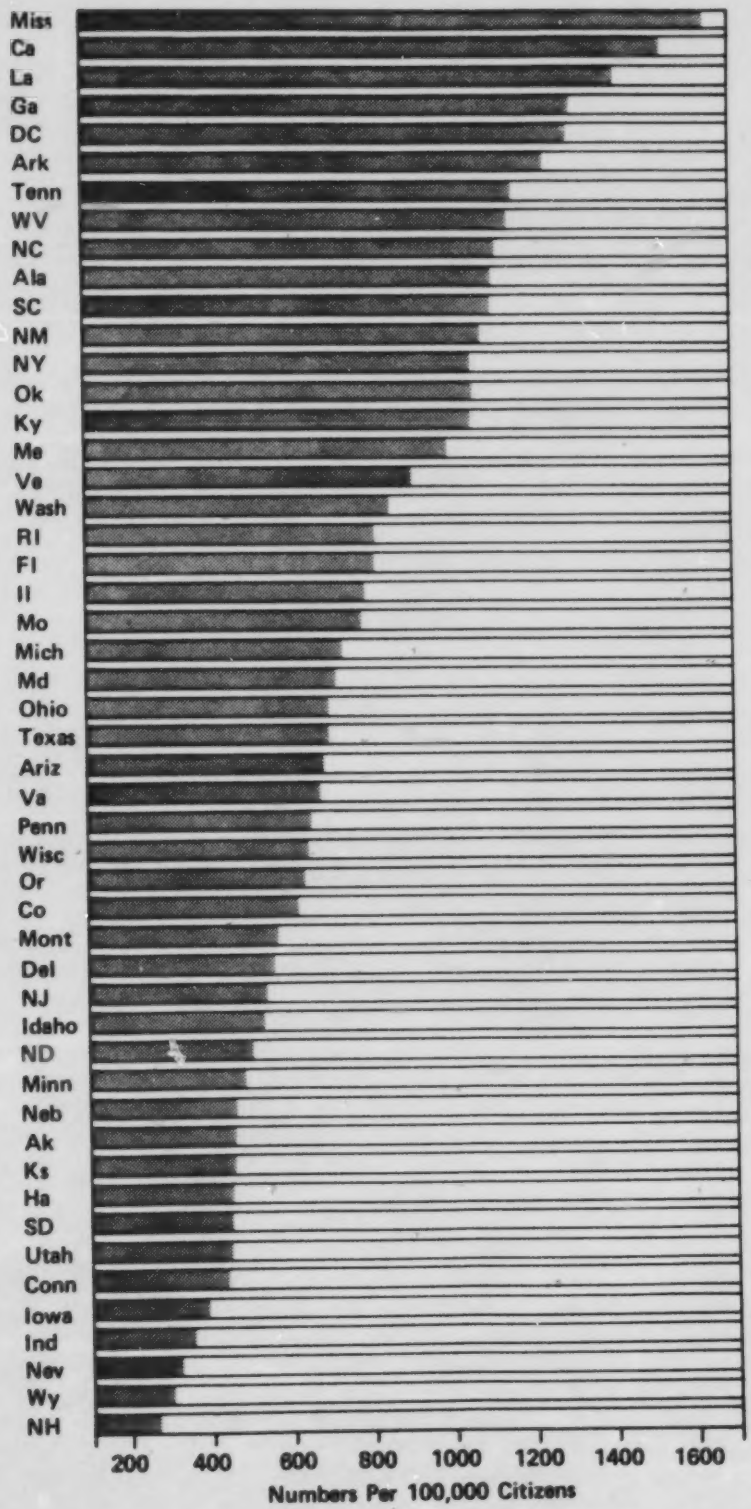
Recommendation: SSA should discontinue the use of standardized denial notices and improve procedures for informing claimants of the specific reasons for the denial of benefits. Provision also should be made for a face-to-face meeting between the claimant and an SSA representative when a denial appeal is filed.

Data presented in Figure III-1 (p. 22) on the proportion of persons enrolled in the SSI program shows drastic interstate differences. For instance, more than six times as many adults per 100,000 population are enrolled in the program in Mississippi than in New Hampshire. In addition, the per capita enrollment of children in Louisiana is almost 15 times as great as the enrollment of children in Hawaii (see Figure III-2 on p. 23).

Variation in enrollment rates may result from inequities in the disability determination process or from a variety of other factors. For example, at least some interstate variations can be traced to the fact that some states,

Figure III - 1

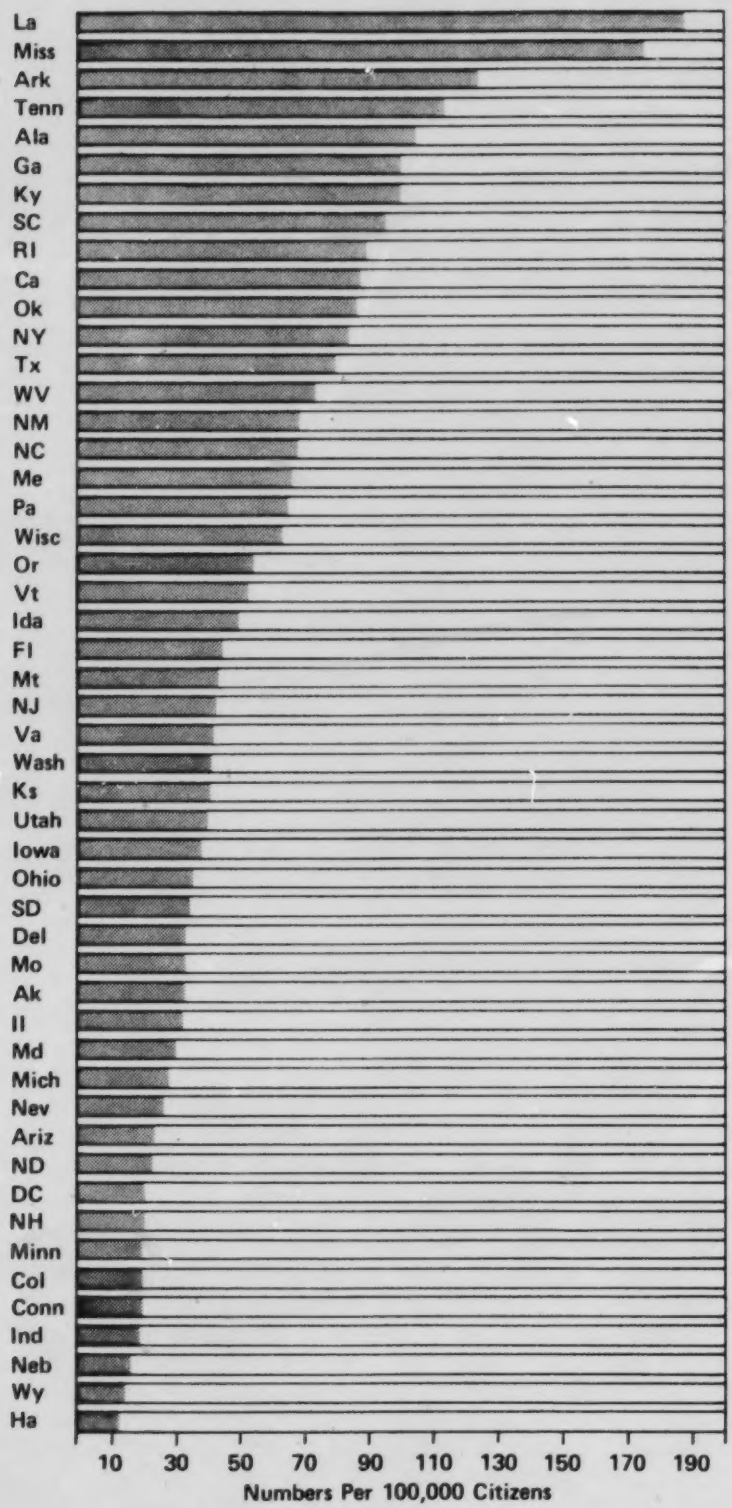
States Ranked By The Number Of Adult Disabled SSI Recipients, Per 100,000 Population (1975-76)



Social Security Administration, "Supplemental Security Income State and County Data, "Baltimore, Maryland: June, 1976; Council of State Governments, *Book of the States*, Kentucky: 1976.

Figure III - 2

States Ranked By The Number Of Children Who Are Disabled SSI Recipients, Per 100,000 Population (1975-76)



Social Security Administration, "Supplemental Security Income State and County Data," Baltimore, Maryland: June, 1976; Council of State Governments, *Book of the States*, Kentucky: 1976.

under the old APTD program, used disability tests which were more liberal than the current federal definition; as a result, a considerable number of recipients eligible for APTD benefits in December, 1973, were "grandfathered" into the SSI program even though they would be unable to meet the current federal test of disability. Economic conditions within a state and the intensity of outreach efforts by SSA district offices will also influence the relative number of recipients in any given jurisdiction. Whether the combination of these factors constitute a sufficient explanation of the existing interstate differences in enrollment rates is the subject of some debate.

Recommendation: The wide variations between states in per capita enrollments of children and adults in the SSI program should be analyzed to determine whether there is inconsistent and inequitable application of the current federal test of disability. Congress should mandate that SSA complete such an in-depth analysis and report its findings at the earliest possible date.*

*Such a comprehensive study of the reasons for interstate variations in SSI enrollment statistics is beyond the scope of the present study. However, due to the fundamental questions raised in this preliminary analysis, the project staff has awarded a contract to the Human Services Research Institute, Inc., to study the factors associated with such interstate variations. The results of HSRI's work should make it possible to pinpoint the reasons for the variations and determine the precise direction and scope of the recommended study by Congress and the Administration.

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CHAPTER IV

ELIGIBILITY FOR REHABILITATION SERVICES

The purpose of the rehabilitation provisions in Title II (SSDI) and Title XVI (SSI) of the Social Security Act is to enable a maximum number of recipients to engage in gainful employment and, thereby, eliminate the need for federal disability assistance. It is quite clear from the legislative history that Congress intends expenditures for rehabilitation services to be offset by the savings in SSDI and SSI benefits which would otherwise be paid to rehabilitated recipients.

In order to insure that recipients who can be rehabilitated are in fact rehabilitated, current law stipulates that a recipient who refuses will lose his eligibility for SSI benefits and/or have his Social Security benefits withheld.* These services—vocational rehabilitation services (VR) for adult recipents** and crippled children's services (CCS) for childhood recipients under age 16—are provided by state agencies with different operating objectives and functional capabilities. In order to understand these differences and the problems caused by the lack of a clear set of national goals and implementing strategies, this chapter will examine restrictions on the use of rehabilitation funds, the objectives of the SSI and SSDI rehabilitation programs, screening criteria for VR and CCS services, and the referral procedures themselves.

I. REHABILITATION SERVICES FOR ADULTS.

Benefit Termination vs. Rehabilitation: A Conflict in Federal Goals. In the 1965 amendments to the Social Security Act (P.L. 89-97), Congress authorized the use of trust funds to reimburse the states for 100 percent of the cost of providing rehabilitation services to SSDI beneficiaries. Under the initial provision, the total reimbursement in any year was limited to one percent of the amount of disability benefits paid out by the trust funds during the previous year. Beginning in FY 1973, Congress increased the authorization for use of trust funds to 1.25 percent and then to 1.5 percent for fiscal year 1974 and subsequent years. An estimated $96.3 million will be used during FY 1978 to rehabilitate disabled and blind Social Security recipients.

A parallel authorization for rehabilitation services to disabled and blind recipients was contained in the 1972 legislation establishing the Supplemental Security Income (SSI) program (P.L. 92-603). The only major difference in the SSI rehabilitation language was that the cost of such services was to be paid for from general revenues rather than from trust fund accumulations. In FY 1978, $75,180,000 has been appropriated for this purpose.

SSA administrative policies implementing the rehabilitation provisions of Titles II and XVI provide that the state vocational rehabilitation agency must certify that a recipient meets the following conditions:

- has a disabling physical or mental impairment that will not outrun the effect of vocational rehabilitation services or keep the recipient from productive activity;
- has a disability that is expected to remain at a level of severity unless rehabilitation is provided;
- has a reasonable expectation of being restored to productive activity through the provision of rehabilitation services;
- has a reasonable expectation of engaging in a period of productive work which will be long enough so that the benefits saved will offset the cost of planned services.

In all cases, the recipient's VR goal must be earnings commensurate with a determination of substantial gainful activity (SGA)*—presently set at $200 a month—and leading to the elimination of benefits. SSI recipients and Social Security beneficiaries who do not meet these

*The Title II and Title XVI penalties for refusing vocational rehabilitation services are technically different. The Title II sanction permits continued eligibility, but benefits are withheld for the months the beneficiary refuses services. In contrast, SSI recipients who refuse VR services are declared ineligible to receive benefits. Under both titles the penalty cannot be imposed if a beneficiary has "good cause" for refusing VR services.

**Since the vast majority of persons referred for vocational rehabilitation services are 18 years of age or over, the word "adult" is used throughout this chapter to indicate persons referred or accepted for vocational rehabilitation services. It should be noted, however, that the minimum age for acceptance into the VR system varies from state to state and, therefore, many children under age 16 are referred to both the state VR agency and the state agency responsible for administering crippled children's services. In addition, SSA has established a special procedure for flagging the records of SSI recipients under the state's minimum age so that such children can be referred for vocational rehabilitation services when they attain the required age.

*See Chapter V for a discussion of the concept of "substantial gainful activity."

conditions are ineligible for rehabilitation services funded through Title II trust funds or Title XVI appropriations; however, they still may qualify for services under the basic federal-state vocational rehabilitation program.

In 1976, a GAO analysis of some 350 cases studied under the SSDI beneficiary rehabilitation program revealed that trust fund savings were considerably lower—$1.15 for every $1 of rehabilitation service expenditures—than DHEW's estimate of $2.50 for every $1 spent on rehabilitation. GAO concluded that SSA may be overstating program savings attributable to SSDI rehabilitation effort.* This finding induced the Ford and the Carter Administrations to impose successive 10 percent cuts in beneficiary rehabilitation program funds. On the assumption that problems found in the operation of the SSDI program applied to the SSI program as well, the 10 percent reduction was also applied to Title XVI appropriations for rehabilitation services.[2] This reduction continues to impose a serious limitation on the states' efforts to rehabilitate SSI and SSDI recipients.

From the vantage point of developmentally disabled individuals, however, perhaps the major weakness in the federal government's current efforts to rehabilitate SSI and SSDI recipients is the fact that the program focuses exclusively on persons who are perceived to be capable of achieving a vocational objective. This legislative policy effectively excludes almost all developmentally disabled recipients from participation in the rehabilitation program since most individuals with severe and chronic impairments originating in childhood require prevocational services before they can qualify as candidates for vocational training.

In addition, limiting services to Title II and Title XVI recipients with strict vocational goals ignores the recent legislative emphasis on increasing the proportion of federal resources made available through the basic rehabilitation program to serve severely handicapped clients. Certainly, the SSDI and SSI disability caseloads contain many severely handicapped individuals of the type Congress was thinking about in 1973 when it mandated that state rehabilitation agencies give top priority to serving the most severely handicapped (P.L. 93-112).

Indeed, the Rehabilitation Act of 1973, as amended, permits state rehabilitation agencies to accept clients for services who are pursuing such goals as homemaker or part-time employment. Also, state agencies are encouraged to provide work evaluation services for periods extending up to 18 months simply to determine whether a handicapped individual has work potential. By depriving state rehabilitation agencies of the flexibility to use Title II and Title XVI funds in this way, Congress is denying many severely handicapped SSI and SSDI recipients appropriate access to rehabilitation services and the dignity which accompanies holding a job.

Recommendation: The goals and objectives of federally funded rehabilitation programs for the disabled under the Rehabilitation Act of 1973 and the SSDI and SSI Beneficiary Rehabilitation Programs should be more closely coordinated in order to give an increased number of severely disabled persons access to needed services.

Recommendation: Congress and HEW should strengthen the role of state VR agencies in the rehabilitation of SSDI and SSI recipients by authorizing the use of Title II and Title XVI funds for rehabilitation services leading to increased earnings and a consequent reduction of benefits.

Procedure for Referral to Rehabilitation Services. Applications for SSDI and SSI benefits are filed in the local SSA District Office. Once the eligibility determination review has begun, the applicant's file is forwarded to a state Disability Determination Service (DDS). In most states the DDS screens for vocational rehabilitation suitability while it is preparing the disability determination. In a few states (e.g., New York), however, a special unit from the state VR agency is responsible for vocational screening. In any event, each disabled individual applying for benefits is screened for referral to rehabilitation services whether the application for SSDI and SSI is allowed or denied.

Screening Criteria: A task force, consisting of representatives from the Social Security Administration, the Rehabilitation Services Administration, the Council of State Administrators of Vocational Rehabilitation and state Disability Determination Services developed guidelines for use by the states in screening SSI and SSDI applicants. While these guidelines are promulgated by SSA, states are given the option of replacing or modifying them with their own intra-state criteria. However, in the absence of such modified or special criteria, SSA insists that the national guidelines be applied. According to a recent survey, the national criteria are being used, without modification, by 35

*It should be pointed out, however, that GAO's findings were based on an examination of a small sample of terminations from a different reporting period from the one covered in SSA's latest cost/benefit report.

DDS's while modified or special criteria are being used in 18 jurisdictions.

SSA screening guidelines are divided into three categories: automatic screen-in criteria, automatic screen-out criteria, and the screening table.

Automatic Screen-in Criteria. If the recipient meets any of the following criteria, the guidelines recommend referral to the state vocational rehabilitation agency:

- the applicant is between age 15 and 45 (unless voided by evidence as noted in Automatic Screen-out criteria);
- the file reflects the fact that the applicant has good potential for successful adjustment to work with appropriate rehabilitation services.
- the primary disabling condition has a favorable prognosis or can be corrected or substantially reduced with the aid of physical restoration or other medical treatment;
- the file contains definite evidence that the applicant can benefit from vocational rehabilitation services (e.g., statement from a physician or consultant);
- the applicant is working despite an impairment and is obviously under-employed;
- the applicant is scheduled for vocational assessment outside the DDS;
- the individual shows rehabilitation potential because of improvement in his medical condition; or
- the applicant has a plan for achieving self-support.

Automatic Screen-out Criteria: If, in the judgment of the Disability Determination Service the recipient has a physical or mental impairment so severe that work adjustment, training, or employment would be precluded, the individual is not referred for vocational rehabilitation services.

Screening Table: When a case does not meet either the automatic screen-in or screen-out criteria, the screening table is used to identify those additional factors which need to be considered. The screening table lists factors for consideration at three graduated levels of vocation potential: excellent, good, and guarded (see Figure IV-1 on p. 30).

When the screening table evaluation reveals three or more factors listed in either the excellent or good columns, the guidelines recommend that a referral be made unless there are specific contraindications. Similarly, if the factors do not fall within the referral pattern but DDS or VR officials feel that the individual has vocational rehabilitation potential, a referral is made.

In addition to this initial, gross screening, twenty-two state vocational rehabilitation agencies currently conduct a secondary screening. The purpose of this follow-up screen is to help agency officials to make more accurate and informed decisions on which SSI and SSDI recipients should receive VR services.

Interstate Differences in Referral Rates. Table IV-1 contains a state-by-state comparison of referral or "screen in" rates for Title XVI rehabilitation services. Note that the rate of referral to the state vocational rehabilitation agency varies from a high of 54.9 percent in West Virginia to a low of 11.7 percent in Delaware. The table also presents the same information by federal region where the referral rate varies from 34.8 percent in the Philadelphia region to 18 percent in the San Francisco region (see p. 31).

There may be many reasons for these state-by-state differences in referral rates. The screening criteria may be unclear or structured in a way which does not allow states to make uniform interpretations. Variations in the assignment of screening responsibility (i.e., by DDS staff or by state VR personnel attached to the DDS) and the feedback from secondary screening also may account for some of the differences.

In an attempt to reduce the interstate differences in referral rates attributable to the screening criteria, a task force comprised of SSA and RSA representatives was recently formed to revise the existing screening criteria.* Of course, it will be some time before revised criteria is completed, tested and implemented nationwide. In the meantime, a new VR information system was implemented on January 1, 1977, to track each SSI and SSDI recipient from the point of referral through the state vocational rehabilitation process until the case is closed. This tracking system will provide information regarding the characteristics of those recipients screened out by the VR agency and, thus, aid in the development of more effective screening techniques and policies. Again, however, it will be approximately one year before any information is retrievable from this new system.

The variations in referral rates may also be attributable to geographic differences in the density or location of the severely disabled population. Interstate differences in age distribution of the population also may account for variations in VR referral rates since one would expect

*This task force, consisting of representatives from SSA, RSA, the Council of State Administrators of Vocational Rehabilitation and state DDS's, met in Washington, D. C., on September 12-16, 1977. A draft revision of the national screening criteria was developed at this meeting. The draft revised criteria are scheduled to be tested in several states.

Figure IV - 1
Screening Table

	Age	Academic Level or Eq.	Motivation	Mental Aptitude	Activity Level - Physical Limits	Medical Prognosis	Work History	Work Performance
Excellent	Under 36	Grade 12 and Up	Positive	High	Minor	Favorable	Stable	Light
Good	36-50	8-11	Passive	Average	Moderate	Stable	Fair	Moderate
Guarded								

Social Security Administration, *Claims Manual*, Baltimore, Maryland: January, 1977.

fewer referrals among disabled SSI and SSDI recipients who are fifty years of age or older. As a result, certain geographic areas of the country may have a higher per capita rate of severely disabled persons.

The bookkeeping or program accounting practices of the Disability Determination Service offices also may be a factor influencing the percentage of SSI recipients referred to vocational rehabilitation. For instance, persons approved for SSI benefits who are already receiving VR services may be counted as referrals to VR in some states but not in others. Another possible explanation is that states with relatively low referral rates may make a more rigorous effort to screen out non-eligible.*

Finally, the workload and resource commitments of the state vocational rehabilitation agency can have a significant impact on the relative number of SSI and SSDI recipients referred. A relatively understaffed state agency, for example, may be forced to allocate fewer and/or less qualified personnel to the screening task which is likely to affect both the quantity and quality of referrals.

*Such states could be expected to have relatively high rates of acceptance for VR services once recipients were referred.

Low Rate of Acceptance by Vocational Rehabilitation Agencies. During the past calendar year, the Rehabilitation Services Administration reports that 477,000 clients were qualified to receive SSI benefits. Of these, 130,000 were referred for vocational rehabilitation services. State VR agencies subsequently accepted 35,000 of those referred (i.e., 27 percent of those referred were actually accepted for services by state vocational rehabilitation agencies). Overall, 66 percent of all clients rejected for vocational rehabilitation services in FY 1976 were Title II and Title XVI referrals.

The relatively low acceptance rate may be caused by several factors. The national screening criteria may not correspond with the VR acceptance criteria. Changes may need to be made in the screening criteria to bring them in line with those generally used by state VR agencies for accepting clients, and/or the VR criteria may need to be less restrictive, thereby opening the doors to VR service to more severely disabled individuals.

Another possible factor holding down the number of referrals accepted by state vocational rehabilitation agencies may be that counselors do not understand the specific rehabilitation needs of SSI and SSDI recipients. Limited training opportunities have been offered to VR personnel which would help them to better serve this population.

TABLE IV-1

SSI Applicants Referred to State Vocational Rehabilitation Agencies

(for period ending March, 1977)

State	Qualified Applicants	Number Referred	Percent Referred
West Virginia	1989	1091	54.9
Virginia	4561	2407	52.8
Kentucky	3428	1496	42.9
North Dakota	270	110	40.7
Hawaii	448	170	37.9
South Carolina	4155	1310	37.0
Minnesota	1602	586	36.6
Illinois	8272	2796	33.8
Wisconsin	2937	961	32.7
New York	22182	8822	30.8
Utah	495	151	30.5
Kansas	1088	328	30.1
Missouri	4238	1264	29.8
Maryland	2638	783	29.7
Montana	452	131	29.0
Pennsylvania	11325	3250	28.7
Arkansas	188	43	25.6
Alabama	4562	1158	25.3
Oregon	1274	321	25.2
New Jersey	6845	1688	24.7
Nebraska	896	167	24.6
Massachusetts	5740	1360	23.7
Texas	11814	2622	22.8
Idaho	420	95	22.5
Michigan	5900	1316	22.3
Indiana	2965	659	22.2
Mississippi	3613	783	21.7
Rhode Island	621	134	21.6
Maine	893	180	20.2
North Carolina	5892	1539	20.1
Wyoming	121	24	19.8
Florida	9064	1754	19.4
Oklahoma	2410	466	19.3
Georgia	7226	1387	19.2
South Dakota	542	104	19.2
Washington	2874	521	18.7
Nevada	573	107	18.7
Louisiana	8995	1299	18.6
California	28752	5191	18.1
New Mexico	1285	231	18.0
Colorado	1979	35[illegible]	17.2
Iowa	1853	283	17.1
District of Columbia	1394	235	16.9
Arkansas	2837	434	15.3
Vermont	473	71	15.0

TABLE IV-1 (continued)

SSI Applicants Referred to State Vocational Rehabilitation Agencies

(for period ending March, 1977)

State	Qualified Applicants	Number Referred	Percent Referred
Tennessee	4862	847	13.1
Arizona	2043	266	13.0
Ohio	8111	1046	12.9
Connecticut	1691	206	12.2
New Hampshire	352	42	11.9
Delaware	856	100	11.7
HEW Regions			
Region III (Del., Wash., D.C., Md., Penn., Va., and W.V.)	22783	7866	34.8
Region II (N.Y., N.J., P.R., and V.I.)	29027	8510	29.3
Region V (Ill., Ind., Minn., Mich., Ohio, and Wis.)	29787	7364	24.7
Region IV (Ala., Fla., Ga., Kty., Miss., N.C., S.C., and Tenn.)	42852	10072	
Region VII (Iowa, Kan., Mo., and Neb.)	7675	1784	23.2
Region VIII (Col., Mont., N.D. S.D., Utah, and Wy.)	3858	873	22.8
Region X (Alaska, Id., Ore., and Wash.)	4846	980	21.1
Region I (Conn., Maine, Mass., N.H., R.I., and Vt.)	9770	1993	20.4
Region VI (Ark., La., N.M., Okla., and Tex.)	25141	5052	20.1
Region IX (Ariz., Calif., Ha., Nev., Guam, and Amer. Samoa)	31816	5734	18.0

Source: Transmittal Memorandum No. 108, Office of Program Operations, Social Security Administration, April 14, 1977.

Restrictions on the number of Title XVI rehabilitation dollars and the ways in which these funds may be used are other factors influencing the VR acceptance rate. The rehabilitation of SSI and SSDI recipients who do not meet SSA's strict criteria must be financed by federal-state VR program funds, which are already in short supply.

Large caseloads and pressure to maximize the number of case closures are frequently cited reasons why vocational rehabilitation counselors are unable to serve more severely handicapped clients. Such clients generally require more intensive counselor involvement, special equipment, facilities and programs, and longer, more costly, periods of training.

Beginning in fiscal year 1977, the formula allocating SSI/VR funds to the states included a weighted factor for SSI/VR clients classed as rehabilitated. This weighting is intended to compensate the state vocational rehabilitation agency for the extraordinary costs associated with serving SSI recipients whose rehabilitation requires more time and resources.[13] Such a performance factor is not included in the current formula for allocating SSDI rehabilitation funds, however, consideration is being given to incorporating this factor into the formula.

Recommendation: Congress should require SSA, in cooperation with the Rehabilitation Services Administration, to complete an in-depth analysis of the reasons for the wide variations between states in the rates of referral and acceptance of children and adults for rehabilitation services.* Regulations should be issued to insure interstate consistency in the referral process.

2. REHABILITATION SERVICES FOR CHILDREN. While authorizing funds to reimburse the states for rehabilitation services to SSI recipients, Congress made no special provision in the 1972 legislation establishing the Supplemental Security Income program (P.L. 92-603) for services to SSI eligible children. The original law simply mandated that all SSI recipients, including children, be referred to the state vocational rehabilitation agency for possible services.

Although the federal Rehabilitation Act, as amended, no longer contains a minimum age for the provision of vocational rehabilitation services, in practice most states treat a child under 14, 15 or 16 years of age as ineligible for such services.* Therefore, it was no surprise when a 1976 study conducted by the National Council of Organizations of Children and Youth revealed that very few SSI recipients under 16 years of age were receiving rehabilitation services. The authors of the study concluded: ". . . that the SSA commitment to ensuring VR services to SSI children is virtually non-existent, that the objectives of mandatory referral of SSI children to VR are confused in law and in the minds of SSA and VR workers, and thus that the explicit linkage of VR to SSI as mandated by Title XVI is not now having the effect of improving coordination of early and continuous services to the disabled child."[6]

In 1976, Congress responded to the lack of federal assistance for services to SSI eligible children by adding Section 1615 to the Social Security Act. Under Section 1615, SSA is responsible for assuring that all disabled SSI recipients under age 16 are referred to the state crippled children's agency or to another appropriate state agency designated by the Governor.** In addition, $30 million is authorized to assist the states in counseling, referring and monitoring the quality of services rendered to SSI recipients under 16 years of age and to finance services to children under seven (as well as older children who have never attended school).

Under this so-called Mikva Amendment*** the designated state agency is responsible for administering a state plan which must include:

- provision for counseling of disabled children and their families;
- establishment of individual service plans for children under 16;
- monitoring to assure adherence to the plans; and
- provision for services to children under age seven and children who have never been in school but who require preparation to take advantage of educational services.

As of October 15, 1977, a total of 35 states had designated agencies to administer this Section 1615 disabled

*In order to identify more precisely the reasons for the wide interstate variations in VR referral and acceptance rates, the project staff has contracted with the Human Services Research Institute, Inc., to complete an indepth analysis of the problems associated with the referral acceptance rates.

*According to SSA's latest survey, all states except New Mexico impose a minimum age for receipt of vocational rehabilitation services. The distribution is as follows: age 13 - one state; age 14 - three states; age 14 1/2 - one state; age 15 - twenty-five states; age 15 1/2 - one state; and age 16 - nineteen states.

**The referral process is actually carried out by the state DDS under contract with SSA.

***Section 1615 of the Act is based on an amendment originally introduced by Representative Abner J. Mikva (D-Ill.).

children's program. Of this total, 32 were crippled children's agencies. However, only five states had approved state plans as of that date.

Funds are allocated among the states on the basis of the relative number of children aged six and under in each state. Up to 10 percent of the allocation can be used for counseling, referral, and monitoring of programs for children 16 and under. The remaining 90 percent of the funds must be used for services to children under age seven and those who have never been in school. As in the case of vocational rehabilitation services, there is no state matching requirement for Section 1615 grants.

Referral of SSI Children for Services. Under interim program guidelines issued by HEW's Health Services Administration, the state Disability Determination Services (DDS) would play a major role in referring eligible children to the state agency responsible for administering Section 1615 funds. The DDS, which in most instances has no direct contact with SSI applicants, is only required to send a written referral notice to parents informing them of the availability of services.

SSA appears to have adopted a "consumer strategy" of service coordination under which responsibility for tailoring services to the needs of the child will fall to the parents. Under such a strategy coordination of services is accomplished by the parent who "shops in the marketplace of services." The problem with this strategy is that it assumes that consumers are knowledgeable about service options and powerful enough to access needed services. Unfortunately, these assumptions are not always valid. A recent report by the Developmental Disability Technical Assistance System (DDTAS) concludes that under HEW's proposed outreach and referral plan, only a small proportion of eligible children will be served. These will be the children,

> ". . . whose parents are able to read and comprehend the written notice and who understand the nature and purpose of the program and who intuit how it can help their child; whose parents have transportation resources to go to the agency; whose parents have telephones to make inquiries; whose parents have time to travel to the agency to enroll and receive services; whose parents have resources to care for other children left at home while enrolling their child. Those served will also include children who have advocates, especially institutional advocates, who have already demonstrated an ability to enroll children for SSI at a much better rate than parents of eligible children in communities."[4]

Recommendation: The Department of Health, Education, and Welfare should strengthen procedures for identifying and referring SSI childhood recipients to appropriate service programs by delegating case finding and referral responsibilities to the local SSA District Office rather than to the state Disability Determination Service.* In addition, the practice of out-stationing state/county welfare agency personnel in Social Security District Offices and other attempts to establish closer working relations between the federal SSI and state welfare systems should be encouraged. The responsibility for furnishing social services to SSI recipients should rest with the state/local welfare office. However, the SSA District Office personnel must see that applicants/recipients in need of such services are counseled and referred to the appropriate state/county office.

Coordination of Services. The HSA guidelines indicate that state Section 1615 plans must provide for "coordination with other agencies serving disabled children." The following federal-state programs are to be included in coordination activities: vocational rehabilitation, education of the handicapped, public assistance, medical assistance (including the EPSDT program), social services, developmental disabilities, maternal and child health, crippled children's services, comprehensive health planning, mental health, and services to the blind.

The guidelines provide that the principal means for achieving coordination is a written agreement between the state agency and each of these programs. This agreement must include a statement of mutual objectives and responsibilities, the services offered by each agency, and arrangements for reciprocal referrals, payment, liaison between agencies, and periodic review of agreements.

Given the major barriers to effective coordination of services on behalf of severely disabled children at all levels of government, it seems doubtful that the goal of effective, client-centered coordination can be achieved through the Section 1615 program.

Recommendation: DHEW should fund a series of model statewide and areawide projects to demonstrate more effective methods for insuring that SSI eligible children who are referred for services actually receive the services they need in the proper sequence and appropriate degree of intensity. Since nearly 80 percent of all children

*As part of a contractual study commissioned by the project staff, Human Services Research Institute will be analyzing problems surrounding the Section 1615 referral process as it is being developed in four selected states.

thus far found eligible for SSI benefits are developmentally disabled, the potential of having the federal-state Developmental Disabilities program play this coordinative role should be carefully explored.

Individual Service Plans. Section 1615 requires that an individual service plan be developed on each SSI childhood recipient who is referred to the designated state agency. HSA interim guidelines stipulate that this plan must consist of a statement of the child's medical, educational, social, developmental, and rehabilitative needs, the long and short term goals to be achieved, the services to be utilized, and the means for evaluating the success of the plan. The plan is to be developed by representatives of the program(s) primarily responsible for delivering or coordinating services, and the child or parent(s). The plan must also "provide for a program coordinator who will be responsible for implementation of the individual service plan and for evaluating its impact on the disability."[8]

Clearly, the individual program plan can be an effective mechanism for assuring that severely disabled children actually receive the multiplicity of services they are likely to require over a span of many years (if not the child's entire lifetime). However, in recent years, individual plan requirements have become something of a fad in federal legislation. At the present time, besides the requirement in Section 1615, individual plans are mandated for handicapped recipients of services under the Education for All Handicapped Children Act (P.L. 94-142), the Developmental Disabilities Act (P.L. 94-103), the Rehabilitation Act (P.L. 93-112), the Civilian Health and Medical Program for the Uniformed Services (CHAMPUS) and in Intermediate Care Facilities for the Developmentally Disabled, to name just a few. The detailed requirements of these individualized plans are not uniform. Since they will be applied to the same group of multi-handicapped children at the point of service delivery, it is important that coordination between the federal, state and local agencies responsible for developing and executing the various service plans be improved.*

*The project staff is in the process of preparing a comparative analysis of the statutory and regulatory provisions of these various individualized planning requirements and the efforts thus far to assess their impact.

Recommendation: Congress should mandate that the federal offices administering the individualized program planning requirements work together to eliminate duplication, conflict, and confusion surrounding the responsibility for carrying out this function. The Secretary of Health, Education, and Welfare should appoint an intra-departmental task force to address these issues.

Provision of Services. Section 1615 requires that disabled children who are six and under, or who have never attended public school, be provided with "medical, social, developmental and rehabilitation services, if those services reasonably promise to enhance the child's ability to benefit from subsequent training or otherwise enhance opportunity for self-support as an adult."

Each state must appoint a "lead agency" which is responsible for assuring, through coordination and advocacy, that a full range of services is available to meet each child's needs. These services must include, at least, "screening, diagnosis, evaluation, home care, parental counseling, and training, medical and surgical care, hospitalization, after care and educational, social, developmental and rehabilitative services as required."

Under the interim guidelines, it is not clear whether a child must be receiving SSI payments or only be considered eligible for payments in order to have his or her rehabilitation services paid for from Section 1615 funds. If the actual receipt of SSI benefits is required, children whose payments are suspended due to changes in parental income or resources will find that funding for rehabilitation services is also terminated. This could result in unnecessary discontinuities in services to severely disabled children from families with marginal economic means. In addition, Section 1615 funds can only be used to pay for services after all other federal/state/local resources have been exhausted. The interim guidelines do not specify who is responsible for ensuring that the designated state agency and other federally funded programs actually deliver the necessary services and don't just "pass the buck" between programs.

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CHAPTER V

INCENTIVES AND DISINCENTIVES TO EMPLOYMENT

In this chapter we will explore the implication of various provisions of the Social Security and Supplemental Security Income programs which are designed to induce or assist disabled beneficiaries to enter (or re-enter) the work force. These provisions will be considered in light of the unique habilitative and vocational training needs of developmentally disabled persons.

Any discussion of the vocational potential of the developmentally disabled population must begin with the premise that the severity and chronicity of the individual's impairments usually constitutes a major barrier to the achievement of economic independence. For a significant portion of the target population this barrier, in all likelihood, will prove to be insurmountable. Indeed, it has been argued that a system which tries to force severely disabled persons, including developmentally disabled persons, to work and measure their achievement in economic terms, may do more harm than good.[17]

Nonetheless, it is important to recognize that the work ethic is deeply imbedded in our American system of social values. Therefore policies which discourage disabled persons from engaging in meaningful work or obtaining the necessary supportive services which will permit them to hold a job deprive the disabled of a basic sense of personal fulfillment and isolate them from the mainstream of society.

Disability is a highly individualistic phenomena. A given set of physical and/or mental impairments, combined with social, educational and attitudinal barriers, may add up to lifelong, total dependency for one person and be merely a temporary hurdle to economic and social independence for another individual. The current state of technology is such that it is difficult to predict, with any degree of certainty, which disabled individuals can be vocationally rehabilitated and which cannot.

A major impediment to placing more severely disabled workers into remunerative work is the ambivalent attitudes of the American public. One consequence of this attitudinal barrier was reflected in testimony which the United Cerebral Palsy Associations recently presented before the Senate Subcommittee on the Handicapped. Characterizing past efforts to vocationally habilitate disabled persons as "a history dominated by an expectancy cycle that perpetuates low levels of success and low employment capabilities," the UCPA witness went on to note that "virtually all that has been attempted [in vocational habilitation] has taken place in the context of simple, menial tasks . . . tasks that are labor intensive rather than machine intensive, thereby accentuating the disabilities rather than the capabilities [of the disabled person]."[16] In a similar vein, Ozawa and Lindsey concluded, after reviewing the impact of the SSI program on mentally ill recipients, that "the relatively greater economic incentive to stay on SSI than on other types of welfare programs, and wide community acceptance of the program, combine in gentle entrapment of the disabled who might otherwise strive for recovery and reentry into the community."[11]

1. THE DEVELOPMENTALLY DISABLED AND THE DISABLED WORKER. The characteristics and needs of the developmentally disabled recipient of SSI or Social Security benefits are quite different from the typical person disabled during his work years. As Dempsey points out,

> "for the adult population the principal precipitation of disability is seen as the loss of ability to continue to meet long standing demands [of] the environment . . . [By contrast,] developmentally disabled children . . . never had certain abilities or . . . lost abilities early in the developmental years before entering the traditional performance demanding environment of childhood, such as school. For these children there is no loss of abilities which had been used to meet environmental performance demands."[4]

Persons disabled during adulthood require rehabilitation services to restore or compensate for lost abilities. Persons disabled at birth or in early childhood need habilitation services to obtain the skills and abilities they never possessed.

Treitel documents the distinctive characteristics of persons disabled in childhood in his analysis of data drawn from the 1966 Social Security Survey of the

Disabled. He concludes that the consequences of disabling conditions are quite different for children, working-age adults and older persons.[15] The picture presented in the 1966 survey data of adults disabled in childhood is as follows:

> "In terms of functional limitations, a greater proportion of childhood disabled were so functionally limited as to be more physically dependent (23 percent) than those disabled when adults (about 16 percent). Among the severely disabled about half of the childhood disabled were dependent compared to about 30 percent of those disabled later in life.
>
> A smaller proportion of the childhood disabled had minor and moderate degrees of functional limitation but a greater proportion of the childhood disabled were functionally dependent. . . Thus, those disabled in childhood were reported to have more extreme ranges of functional loss than persons who became disabled when adults."[15]

In reflecting on service needs, Treitel concluded that childhood disabilities led to greater dependency than conditions occurring later in life. He stated:

> "From a developmental perspective, people may be seen as passing through a series of social and economic stages in terms of their age: from training for self-maintenance and family life in childhood, to employment and child raising in adulthood, to retirement at an older age. Impairments may interfere with these progressions and lead to alternative personal and social arrangements. A person disabled in childhood may continue to be dependent on his family when an adult; a worker who suffers an injury which prevents employment for an extended period of time may need to establish disability or welfare status in an income maintenance program; an older worker with an impairment may decide on early retirement."[15]

From the point of view of the developmentally disabled person, one of the basic limitations of current SSA efforts to encourage or induce disability beneficiaries to enter the labor force is that most existing work incentives are built upon the assumption that the individual may have residual work capabilities which can be restored. The functional differences between the disabled worker and the childhood disability recipient, for example, are not taken into account in establishing the maximum duration of a trial work period, in ascertaining the legitimacy of pre-vocational objectives under a plan for achieving self-support, or in the treatment of work-related expenses.

Recommendation: Congress should mandate a major collaborative longitudinal study of the effects of Social Security and SSI benefits on the work behavior of various categories, of disabled recipients, including the developmentally disabled recipient, to determine the most appropriate means of assisting individuals who are capable of entering or re-entering the labor market. Such a study should be undertaken jointly by the Departments of Labor and Health, Education, and Welfare and should examine both the incentives and disincentives to entry into the work force by the disabled individual.

Recommendation: The feasibility and need for a separate, identifiable program of benefits for adults disabled in childhood—including a special set of work incentives—should be examined by Congress. One of the advantages of such an approach would be that benefit levels and work incentives could be tailored to the unique needs of this group rather than being inappropriately modeled after provisions for persons disabled during their adult years.

An illustration of the dangers inherent in treating all disability recipients as a homogenized group can be found in the so-called "Disability Insurance Amendments of 1977" (H.R. 8057). This measure, introduced by Congressman James A. Burke (D-Mass.) on June 28, 1977, proposes that monthly Social Security payments to young recipients of disability benefits be reduced in order to induce them to either stay off the disability rolls or re-enter the work force. The rationale underlying the Burke bill is that the sharp increase in the minimum Title II benefit and the reduction in the number of quarters of coverage required over the past few years has made it considerably more attractive for workers with marginal employment limitations to seek and retain disability status.

The fact that thousands of adults disabled in childhood, who qualify for benefits under their parents' work record, would also suffer a reduction in Title II benefits is overlooked by proponents of the Burke bill. Reducing the minimum monthly benefit level for young disabled workers may have the effect of forcing some individuals with moderate work limitations back into the work force. However, it is unlikely to induce the developmentally disabled recipient, who typically has no work record, into remunerative employment and, thus, would constitute an unjust penalty. In addition, it should be recognized that adults disabled in childhood are already being penalized

under Title II since their benefits are limited to 50 percent of the primary insurance amount while their parents are alive (i.e., either retired or disabled themselves) and 75 percent after the death of their parents.

Recommendation: Any legislative efforts to restrict the eligibility of younger disabled workers, or to limit payments to this group, should not be applied to adult recipients of SSI or Social Security benefits who were disabled in childhood.

The 24-month "second waiting period" for Medicare benefits is another example of how policies designed for the disabled worker tend to discriminate against Social Security recipients disabled in childhood. In order to qualify for Medicare health and hospitalization benefits, an SSDI recipient must be on the rolls for 24 months. Since there is a five month waiting period to qualify initially for SSDI disability benefits, the total waiting period for Medicare benefits is actually 29 months.

The cost of extending Medicare to the disabled was the major factor which led Congress to mandate an additional 24 month waiting period before SSDI recipients became eligible for such benefits. However, a key rationale for this action was that most disabled workers are eligible for time-limited benefits under workmen's compensation and a variety of private health and disability insurance policies and, therefore, the federal government should not assume the costs of such benefits through the Medicare program. This argument, however, does not apply to childhood disability recipients since very few individuals who qualify on their parents' work record are entitled to workmen's compensation or are covered for chronic health conditions under private insurance policies. It should also be noted that, unlike the typical disabled worker, an adult disabled in childhood generally is not at high risk of hospitalization during the 24 month waiting period.

Recommendation: The 24-month "second waiting period" for Medicare payments should be eliminated for Social Security beneficiaries disabled in childhood.

2. THE PARADOX OF WORK INCENTIVES FOR THE DEVELOPMENTALLY DISABLED INDIVIDUAL. As indicated in Chapter III, an applicant must be unable to engage in substantial gainful activity as the result of a medically determinable disability which is expected to last at least twelve months in order to be eligible for Title II or Title XVI benefits. However, Congress has recognized that the condition of some recipients may improve, new medical or rehabilitation technology may be developed, or societal attitudes toward the handicapped individual may improve to the point where he or she is no longer considered disabled. Because of this potential for change in the degree or consequences of an individual's impairment, and in technological, social, economic, and labor market factors, SSA provides work incentives to get those recipients who are capable of substantial gainful activity back into the work force.

The most fundamental work incentive used by SSA is, quite simply, to deny benefits to individuals who are physically and mentally able to work. The medical disability and substantial gainful activity (SGA) tests which rule out benefits to able-bodied individuals under the Title II and Title XVI programs, therefore, must be viewed as negative work incentives.

Current SSA regulations indicate that average earnings of over $200 a month generally indicate that a recipient is engaged in SGA and, therefore, is not considered "disabled" within the meaning of the law. Average monthly earnings of between $130 to $200 constitutes a gray area in which the individual may or may not be found to meet the SGA test, depending on such circumstances as his work activity, medical evidence of his impairment and other related factors. However, if the individual works in a sheltered workshop or a comparable facility, earnings not exceeding $200 a month normally will not establish the capability to engage in gainful activity. In point of fact, SSA officials indicate that beneficiaries earning under $200 a month, regardless of their work setting, are very rarely found to be engaged in gainful activity.

The current SGA test has not been adjusted in almost five years. In the interim the average earnings of workers covered by Social Security have increased by more than 35 percent and the cost of living has gone up by a comparable amount. As a result, the SGA test is currently so low that it acts as a disincentive to the disabled worker with marginal work skills who wishes to earn his own way.

Recommendation: Congress should eliminate the substantial gainful activity test of disability from the Act and, in its place, use the same earnings limitation and benefit reduction formula applied to aged and blind recipients of SSI. As witnesses representing consumer organizations for the blind and disabled recently told the House Welfare Reform Subcommittee, the current SGA test causes: "(a) unfair treatment of the disabled relative to other welfare categories; (b) a destructive notch

resulting in loss of all income support and Medicaid eligibility if $200 or more is earned; and (c) a perversion of real work incentives."[14] The fact that twice the percentage of blind SSI recipients were employed as of September, 1976, (blind-6.8 percent; disabled-3.1 percent) and had average monthly earnings of over three times as much as their disabled peers (blind-$262.07; disabled-$82.53) suggests that removal of the SGA test might have a favorable impact on the employability of disabled SSI recipients.[18]

Should Congress elect to retain SGA as a factor in determining the eligibility of disabled persons, then, at least, the current income test should be raised substantially and indexed to protect recipients against future cost of living increases.

In this regard, it should be noted that the Social Security Administration recommended in February, 1976, that the SGA test be increased to $250 monthly and indexed in the manner suggested above. Apparently fearful that a higher SGA test would lead to significant increases in the number of eligible beneficiaries, HEW later decided to pigeon-hole the proposed regulations. Ironically, one of the clearest statements of the rationale for raising the earnings test is found in the following quote taken from the February, 1976, regulations: "[T]he [SGA] earnings amounts used are more effective when they are increased consistent with increases in the average earnings of workers in private industry. As the general level of earnings increases, the fixed level guides become less indicative of engagement in the labor market and need to be adjusted."[9]

Should Congress choose this latter approach, the SGA test should be maintained at a level commensurate with 70 percent of the prevailing federal minimum wage. Under such an approach, the monthly SGA test would be approximately $310 in 1978, $338 in 1979, $362 in 1980 and $390 thereafter.*

3. INCOME DISREGARDS AND BENEFIT REDUCTIONS. The intent of Title XVI of the Social Security Act is to promote work by keeping benefit reduction ratios low enough to assure the worker a substantial return from increased earnings. Thus, the first $20 of the monthly income from any source, plus up to $65 of earned income, are not counted in determining whether an individual meets the SSI means test. In addition, the benefit reduction ratio of 1:2 (one dollar loss in benefits for every two dollars earned) is intended to maintain the recipient's incentive to earn additional dollars until he reaches the point where he achieves economic independence. The benefit reduction ratio of 1:4 in the Food Stamp and Section 8 rent subsidy programs are similarly designed.

In fact, however, the combination of a low initial income disregard and relatively high benefit reduction ratio in the SSI program tends to inhibit disabled workers from entering or re-entering the work force. Developmentally disabled individuals are particularly hard hit by these so-called work incentives because they have such marginal employment skills. For example, a recent Labor Department study found that the average earnings of mentally retarded workshop clients were 87¢ an hour in certified workshops and 56¢ an hour in non-certified workshops.[6] Under the current SSI program, the benefit check of a full-time worker earning 87¢ an hour would be reduced by roughly $27 a month.* The worker earning just 60¢ each hour would lose monthly benefits of almost $10. Since a sheltered workshop or similar sub-minimal wage setting will be the highest level of employment many developmentally disabled workers can achieve, it seems unnecessarily punitive to impose an earnings penalty on their already paltry wages.

The lower the benefit reduction ratio, the greater the work incentive. In principle, this is logical. But in practice not every benefit can be reduced in incremental steps. Some benefits are indivisible: either you are entitled to them or you are not. Medicaid is one such program. In most states, the loss of Medicaid benefits coincides with the loss of SSI eligibility and, thus, represents an extreme case of high benefit reduction—a so-called "notch."** In the case of disabled persons, whose health and medical needs are often extensive, this "notch" can be a yawning cavern which swallows up the individual and his resources. Thus, the possibility of losing Medicaid benefits or social services benefits funded under Title XX of the Act may be a major deterent to engaging in remunerative employment.

*Assuming the worker is paid for 40 hours a week for a total of 50 weeks at 70 percent of the federal minimum wage levels specified in the Fair Labor Standards Amendments of 1977 (P.L. 95-151).

*Assum[illegible]e or she worked 40 hours a week and had no other source of income.

**One modifying factor here is the "spent down" feature incorporated by 29 states and the District of Columbia in their Medicaid state plans. Under this plan, the "medically indigent" maintain Medicaid coverage by spending their earnings for medical care down to the level of SSI eligibility. While Medicaid eligibility is maintained, the "spend down" is, in effect, a dollar-for-dollar reduction of earnings. The beneficiary continues to be eligible for Medicaid, but his or her work incentive is destroyed.

4. THE DISINCENTIVE EFFECT OF CUMULATIVE BENEFITS. When a disabled individual qualifies for benefits under several social welfare programs (e.g., SSI, Medicaid, social services, Food Stamps, and a rent subsidy), the interplay between the benefit reduction ratios under these programs can serve as a disincentive to work. The net effect of this phenomenon is that individuals with the most extensive needs, as represented by their utilization of social benefits, have the poorest incentive to enter or re-enter the labor market.

Figure V-1 depicts the career of a hypothetical disabled person who qualifies for and receives SSI, Medicaid, a rent subsidy, and Food Stamps benefits, and whose monthly earnings increase steadily from zero to $425 a month over an 18 month period. A further assumption is made that our hypothetical recipient begins a nine month trial work period at the beginning of the third month and doesn't lose his eligibility for SSI benefits until the end of the fifteenth month.*

Note that with no earnings during the first month our recipient has benefits with a total cash value of $356 (i.e., Food Stamps - $46, rent subsidy - $100, SSI benefits - $167, and Medicaid - $43.) Food Stamps, rent subsidy, and SSI benefits are all reduced as income increases. As a consequence, the cash value of total benefits increases very little. For example, over the first year monthly earnings increase by $275 while the value of total benefits increases only $25 - from $356 to $381. The abrupt drop in total benefits at the end of the fifteenth month illustrates the loss of Medicaid benefits - the infamous "Medicaid notch." At the end of 18 months our hypothetical recipient has earnings of $425 a month, a net increase of just $69 in total benefits over the 18-month period. In other words, our recipient's work incentive included a net gain of only $69 for increasing his earnings from zero to $425 a month.

A Title II beneficiary under the hypothetical example would be somewhat better off than the SSI recipient because Social Security benefits are not reduced until annual earnings exceed $1680. The recipient's earnings would not exceed this "retirement test" until the twelfth month, at which time his benefit would be reduced one dollar for every two dollars earned over $1680. However, at the end of the trial work period, he would be engaging in substantial gainful activity and, therefore, would no longer be eligible for Title II benefits. The net effect would be an even more precipitous drop in total income (see Figure V-1 on p. 42).

5. THE TRIAL WORK PERIOD. The trial work period is intended to give a disabled beneficiary the opportunity to test his ability to work and hold a job. The work a person performs during a TWP, regardless of the level of earnings, is not considered in determining whether he is engaged in substantial gainful activity. However, earnings are still considered in determining the amount of the person's benefits. In other words, income disregards and benefit reduction ratios continue to apply to recipients enrolled in a trial work period.

Under current law each recipient gets only one nine-month trial work period during each episode of disability.* A single nine-month trial may be sufficient for a worker whose episode of disability resulted from a non-chronic disease or disorder which is unlikely to reoccur once the individual is cured or rehabilitated.

But for the developmentally disabled person whose episode of disability is, in all likelihood, life long and whose work adjustment problems are complex, a single nine-month trial work period often will be much too short.

Recommendation: The duration of the trial work period should be extended to 24 months, and a time period should be established within which the entire trial work period must take place or else be recycled to zero.

6. PLAN FOR ACHIEVING SELF-SUPPORT. A plan for achieving self-support is intended to encourage disabled recipients of SSI and SSDI benefits to become economically independent. It does so by permitting a person to retain additional income and accumulate certain resources so that he may receive occupational training, purchase job-related equipment, establish a business, etc. Income and resources necessary to carry out the plan are not counted in determining the amount of the individual's benefit; however, such income and resources are considered in deciding whether the recipient is engaged in substantial gainful activity.

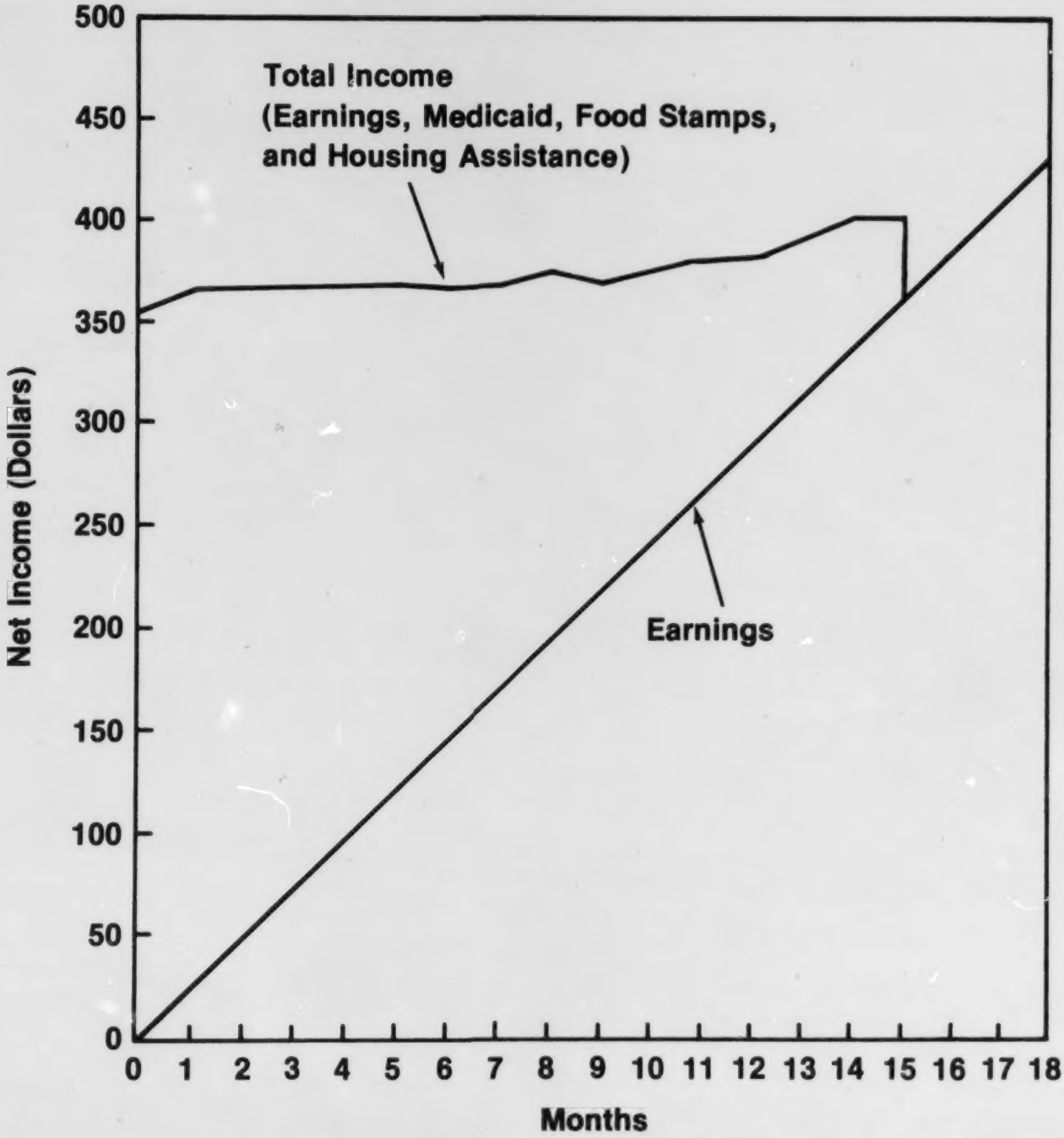
One key feature of the plan for achieving self-support which, for all practical purposes, excludes

*This action has the effect of discounting the individual's earnings in determining whether he is engaged in substantial gainful activity. (See explanation of the Trial Work Period later in this chapter.)

*Even though all payments may be terminated at the end of the trial work period if the recipient is found capable of engaging in substantial gainful activity, his eligibility for SSI benefits continues for an additional 90 days. Thus, he may retain his Medicaid, Social Services, Food Stamps and other benefits related to SSI eligibility for an additional three month period.

Figure V - 1

Relationship Between Earnings and Benefits Under SSI Program



developmentally disabled individuals is that the plan must have a vocational objective. In other words, the plan must focus exclusively on making the SSI or SSDI recipient economically self-sufficient. This is an inappropriate objective for most developmentally disabled persons, who require training to achieve such pre-vocational objectives as money management, the use of public transportation, or independent living as a prelude to the achievement of any vocational goals.

If the plan were to allow recipients to pursue pre-vocational objectives, an additional source of support would be available to help developmentally disabled individuals achieve their program goals. In effect, the recipient could mobilize a greater share of his own resources toward the achievement of pre-vocational objectives.

This limiting feature of the current plan for achieving self-support prevents severely disabled SSI and SSDI recipients from entering the labor market by frustrating their attempts to take the necessary first steps. The irony of this policy is that those individuals who need the greatest amount of assistance to achieve self-sufficiency are excluded from participation.

Recommendation: The Social Security Administration should revise its current policies governing plans for achieving self-support to allow SSI and SSDI recipients to establish legitimate pre-vocational objectives.

7. WORK-RELATED AND LIVING EXPENSES. While current law requires SSA to disregard ". . . expenses reasonably attributable to the earning of any income . . ." in determining the SSI eligibility of blind individuals (Section 1612(b)(4)(A)(ii)) this same provision does not apply to disabled SSI recipients. Many disabled recipients, especially those who are developmentally disabled, incur the same types of extraordinary job-related expenses as blind individuals; therefore, the present Act constitutes a blatant case of discrimination against non-blind, disabled recipients of SSI benefits. For example, specialized transportation services or adaptive devices may spell the difference between whether a cerebral palsied individual with a severe motor involvement is capable of working. There is no sound programmatic justification for allowing blind individuals to deduct such costs and not extending the same privilege to persons with other disabilities. The only rationale which can be offered is that the SSI Trust Fund would have to bear the increased costs associated with extending the provision of Section 1612(b)(4)(A)(ii) to the disabled. However, these short term costs would be offset, at least in part, by the long range savings involved in permitting disabled persons to earn a living and, thus, reduce their dependence on welfare.

Recommendation: Congress should permit SSA to deduct job-related expenses in determining whether non-blind, disabled individuals, under 65 years of age, are entitled to receive SSI benefits.

In addition to disregarding job-related expenses for disabled SSI recipients, the definition of what constitutes an employment related cost needs to be expanded to include transportation, interpreter services and a wide variety of prosthetic devices (specially adapted wheelchairs, symbol boards, special clothing, etc.) which may be necessary to permit a disabled individual to be employed. For some developmentally disabled individuals, permission to deduct such costs may spell the difference between a life of total dependence and the dignity of holding a job.

Recommendation: Congress should authorize an additional monthly increment for blind and disabled SSI recipients who require in-home assistance (i.e., attendant services or social supervison). The amount of this additional payment should be based on the level or intensity of the individual's need for such services. Such a special payment would be similar to the provision in Title 38 of the U. S. Code which authorizes additional monthly benefits for veterans with non-service connected disabilities who require the assistance of an aide or attendant. As is the case with the veterans program, payment of this special, federally financed supplement would be authorized only when a physician has certified that the recipient requires such services to prevent placement in a more costly institutional setting.

8. SHELTERED WORKSHOP EARNINGS. As indicated earlier, when computing the amount of a recipient's benefit payment, SSA disregards the first $20 of monthly income from any source, earned or unearned, plus up to $65 of earned income. By treating the earnings of SSI recipients in sheltered workshops as unearned income, SSA has created a severe work disincentive for thousands of current recipients.

SSA interprets the common law test of an employer-employee relationship to mean that the employer has the right to hire and fire, direct the employee's activities, and control the work product.

These conditions do not apply in a sheltered workshop, SSA officials argue, and therefore, all earnings in excess

of $20 a month trigger a sharp reduction in the recipient's benefit check.

On July 28, 1977, the Senate Finance Committee approved an amendment to the pending Public Assistance Amendment of 1977 (H.R. 7200) which would require the Social Security Administration to treat the wages of sheltered workshop clients as earned income for purposes of SSI eligibility and benefit levels. However, at this writing, it is not clear whether Congress will take final action on H.R. 7200 during its current session.

More recently, the Social Security Administration has issued a change to the Claims Manual which outlines new procedures for determining whether remuneration received by sheltered workshop clients should be treated as earned or unearned income. The new Claims Manual procedure, which as transmitted to the field on November 4, 1977, states that a disabled individual engaged in a rehabilitative-training phase of sheltered work may or may not be found to be engaged in an employee/employer relationship, depending on the circumstances. However, unlike the previous policy, the November 4 issuance makes it clear that "when a handicapped individual continues in some type of a sheltered workshop environment after the completion of this rehabilitative-training program, and receives remuneration for such work activity, then the recipient may be performing services in an employer/employee relationship . . . and may be receiving earned income".[12]

This new policy promises to eliminate the problems which have been raised by workshop operators and client advocates.

Recommendation: Congress and SSA officials should work cooperatively to assure that the legitimate earnings of sheltered workshop clients are treated as earned income for purposes of determining SSI eligibility and the level of monthly benefits.

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CHAPTER VI

THE RELATIONSHIP BETWEEN LIVING ARRANGEMENTS AND BENEFIT LEVELS

In the 1972 legislation authorizing the Supplemental Security Income program (P.L. 92-603), Congress included several provisions which have had the effect of discouraging eligible persons from residing in certain types of living arrangements. Among these provisions were the prohibition against payments to persons in public institutions, the reduction of benefits to recipients "living in the household of another" and the treatment of family income in determining a child's eligibility. Although not originally intended by Congress, the process by which states elect to supplement a recipient's monthly benefit check also has tended to inhibit the range of residential alternatives available to SSI eligible individuals.

The purpose of this chapter is to identify the ways in which current statutory and regulatory policies governing the SSI program tend to influence the recipient's place of residence. Particular attention will be devoted to the ramifications of such policies for providing the continuum of residential living alternatives needed by developmentally disabled individuals.

I. THE IMPACT OF STATE SUPPLEMENTATION. At the time of the enactment of P.L. 92-603, the Supplemental Security Income program was generally viewed as a "federalization" of the former state-operated cash-assistance programs for needy aged, blind and disabled persons. However, Congress did not authorize a total federal takeover of the then existing adult welfare programs; instead, a minimum federal payment level was established for all eligible recipients and each state was permitted to supplement this basic payment to meet the perceived needs of poor elderly, blind and disabled persons within its jurisdiction.

Congress could have elected to set the federal payment level in the original legislation high enough that every eligible recipient would have been assured cash assistance at least equal to the amount received prior to implementation of the SSI program. However, because of the increased federal outlays which would have been necessary to bring all recipients up to the level of the highest payment states, a lower federal payment floor ($130 a month for single individuals and $195 for couples) was established. As a result, states were left with the residual responsibility of providing supplemental benefits to SSI eligible recipients.

One of the important consequences of the decision to permit state supplementation was that the program became considerably more difficult to administer because it retained some historical vestiges of the old OAA, APTD and AB programs. For example, over the years, states with relatively high APTD benefit levels developed a complex set of payment rates to meet special needs among eligible disabled recipients. When the SSI program went into effect these states found themselves in the position of having to develop intricate supplementation schedules and Medicaid eligibility agreements in order to insure disabled individuals that they would not get less benefits than they received under the old state administered APTD program.

Sections 1616 and 1618 of the Social Security Act spell out the procedures for managing state supplemental payments. If a state elects to supplement the monthly benefit levels of certain categories of SSI recipients, it may choose to enter into an agreement with the Social Security Administration under which SSA will manage all optional state payments and also assume the total administrative costs incurred. However, should a state elect federal administration of its state supplemental funds, it can only vary its payment levels within the following prescribed limits:

- by category of recipient (i.e., aged, blind and disabled;
- by up to five variations in living arrangements, and/or;
- by up to three variations according to geographic areas of the state.

In 1973 Congress added to the complexity of the supplementation system by requiring states to guarantee previous recipients of OAA, APTD and AB benefits at least the same payment level they enjoyed in December, 1973 (P.L. 93-66). The purpose of these so-called mandatory supplementation provisions was to protect poor elderly and disabled persons from the loss of benefits when SSI was implemented. Congress later took a series of steps to safeguard Medicaid and Food Stamp

recipients against loss of benefits as a result of their SSI eligibility (P.L. 93-233; P.L. 94-585).

Given the permissible variations in the levels of state supplementation, it would be mathematically possible for SSA to have literally thousands of different payment levels if every state elected federal administration and exercised all its payment alternatives. In practice, however, only seventeen states and the District of Columbia have chosen to have the federal government administer their optional supplemental payments (see Table VI-1). In addition, most states have utilized only a few of the possible payment variations available.

Appendix A, which contains a tabular state-by-state breakdown of payment levels for disabled recipients (including state supplemental payments) by living arrangement, illustrates the significant inter-state variations which exist and the complexities of the current system for state supplementation. The number of living arrangements specified by each state varies from one to fourteen. Forty-two states and the District of Columbia have delineated five or fewer different living arrangements while seven states have specified from six to fourteen living arrangements. A related problem is the lack of common terminology used by the states to describe various living arrangements.

Critics of the current state supplementation system contend that permitting numerous payment variations according to living arrangements, geographical considerations and payment categories tends to add to the complexity of administering the SSI program and undermines the concept of a uniform national payment standard. They argue that Congress never intended the SSI program to fulfill all of the varied needs of aged, blind and disabled persons, citing as evidence the following language in the House Ways and Means Committee's report on the original legislation establishing the program:

> "If a State elects to enter into an agreement under which the Federal Government administers its supplemental payments, it would have to abide by certain conditions. Supplementation would have to be provided to all individuals and families who were eligible under the basic Federal assistance programs except that, at the State's option, it could exclude families with both parents present and able to work (whether or not actually employed) or it could exclude families in which the father is actually employed full time. In addition, the state supplementation would have to be provided under such terms and conditions as the Secretary finds necessary for effective and efficient administration.

TABLE VI-1

Administration of State Supplemental Benefits as of October, 1976

State	Administration of mandatory supplement		Administration of optional supplement	
	Federal	State	Federal	State
Alabama		X		X
Alaska		X		X
Arizona		X		X
Arkansas	X		X	
California	X		X	
Colorado		X		X
Connecticut		X		X
Delaware	X		X	
District of Columbia	X		X	
Florida	X			X
Georgia	X			
Hawaii	X		X	
Idaho		X		X

TABLE VI-1 (continued)

Administration of State Supplemental Benefits
as of October, 1976

State	Administration of mandatory supplement		Administration of optional supplement	
	Federal	State	Federal	State
Illinois		X		X
Indiana		X		
Iowa	X		X	
Kansas	X			
Kentucky		X		X
Louisiana	X			
Maine	X		X	
Maryland	X			X
Massachusetts	X		X	
Michigan	X		X	
Minnesota		X		X
Mississippi	X			
Missouri		X		X
Montana	X		X	
Nebraska		X		X
Nevada	X		X	
New Hampshire		X		X
New Jersey	X		X	
New Mexico		X		X
New York	X		X	
North Carolina		X		
North Dakota		X		X
Ohio	X			X
Oklahoma		X		X
Oregon		X		X
Pennsylvania	X		X	
Rhode Island	X		X	
South Carolina		X		X
South Dakota	X			X
Tennessee	X			
Texas				
Utah		X		X
Vermont	X		X	
Virginia		X		X
Washington	X		X	
West Virginia		X		
Wisconsin	X		X	
Wyoming	X			
TOTALS	28	22	17	25

Source: "The Supplemental Security Income Program," Staff report to the Committee on Finance, U.S. Senate, April, 1977.

> In general, it is anticipated that the same rules and regulations would be applied to both Federal and State supplemental payments with the only difference being the level of such payments. However, the Secretary could agree to a variation affecting only the State supplement **if he finds he can do so without materially increasing his costs of administration and if he finds the variation consistent with the objectives of the program and its efficient administration.**" (emphasis added).[13]

The current supplementation system has also been singled out by many critics as a major cause of the high error rate. Calculating the amount of benefits due any given applicant is an intricate process, involving many decision steps where judgmental or computational errors are possible. This point was made by the staff of the Senate Finance Committee in its recent report on the SSI program. The authors concluded that ". . . the policy decisions made by the Department to allow so many different modalities of state supplementation have unduly complicated the administration of the program and been responsible in large part for the inability to complete work on acceptably functioning systems."[13]

The complexities of the supplementation agreements which have been drawn up between SSA and the states have led to a multitude of major and minor strains on intergovernmental relations. These disputes have exacerbated the already difficult task of effectively and efficiently administering the SSI program.

Given the political and economic barriers to significantly raising the current federal payment standard and the widely varied subsistence needs of disabled individuals, however, it is difficult to conceive how an equitable cash assistance system can be structured without a finely tuned system of state supplementation. The basic reason for the high error rate in the program is not the limitations of computer technology but rather the difficulty in determining which benefit level, adjusted by payment category, state of residence, living arrangement, marital status, etc., should be applied to the particular recipient. After all, the Social Security program and, indeed, the payrolls of many large corporations, are effectively managed despite the existence of thousands of different payment levels and a myriad of deductions and special charges. The difference is that, unlike the SSI program, the various entries can be readily quantified and assigned to the appropriate payee.

In the final analysis, the debate over the management of state supplemental payments must be seen as reflecting differing sets of values. The basic question is: does Congress and the American public want an SSI program which is efficiently and economically managed or a system which meets the needs of aged, blind and disabled recipients.

Recommendation: Congress should carefully review the purposes and structure of state supplemental payments to determine the most equitable and effective approaches to assisting disabled persons to live in the least restrictive living environment compatible with their needs and personal preferences.* The goal should be to strike a reasonable balance between administrative efficiency and appropriately meeting the needs of disabled Americans.

2. THE INTERACTION OF FINANCIAL ASSISTANCE PROGRAMS. As demonstrated in Chapter V, the interaction among various types of cash and in-kind assistance often works to the recipient's disadvantage. In recent years Congress has attempted to eliminate some of the most striking inequities in the treatment of in-kind support and maintenance on behalf of SSI recipients. For example, the so-called Church Amendment (Section 1612(a)(2)(A)(ii) of the Act) provided that any in-kind support and maintenance furnished by a non-profit retirement home or similar institution would not be counted in determining whether a resident of the facility was eligible for SSI benefits or in determining the level of his monthly payments. Similarly, the Keys Amendment (Section 1612(b)(6) of the Act) stated that, after October, 1976, any assistance which is based on need and furnished to, or on behalf of, an individual recipient by a state or local government will not be counted as income to the recipient.

These provisions are generally designed to allow the public and non-profit sectors to play a larger role in financing services to SSI recipients. Eligible persons are permitted to receive in-kind assistance from public and non-profit agencies without having such support eliminate their eligibility or reduce their cash entitlements under the SSI program. However, the piecemeal approach which the Administration and Congress has taken to eliminating the unfair treatment of in-kind support and maintenance has tended to perpetuate some inequities. For example, SSA proposes to narrowly interpret the Keys Amendment by limiting it to activities funded wholly by a

*During the course of its contractual study, the Human Services Research Institute, Inc., will review the impact of state supplemental payments on the provision of services to developmentally disabled persons in various types of institutional and non-institutional living arrangements.

state, or political subdivision of a state, and to those dollars allocated on the basis of economic need only. Likewise, the Church Amendment permits the exclusion of in-kind support on behalf of institutionalized recipients; no similar provision is included for individuals living at home or in other non-institutional settings, although legislation is now pending in Congress to remedy this problem.

Recommendation: The Social Security Administration should promulgate regulations governing the treatment of state or local payments based on need which exclude all forms of assistance furnished to SSI recipients on the basis of economic and social need by a state and local government. In addition, Congress should enact into law the language of Section 111 of the House-passed version of H.R. 7200 which would require SSA to exclude from countable income any contribution made by a non-profit organization on behalf of an SSI recipient living in a non-institutional setting.

3. DEEMING PARENTAL INCOME. Although professionals in the field generally agree that the natural home is the best place of residence for most disabled children, the current process of determining whether an individual under 21 years of age is eligible for SSI benefits acts as a disincentive to maintaining a child at home. Section 1614(f)(2) of the Act directs the Commissioner of Social Security to assume that the income and resources of the parents are available to a child under 21 years of age in deciding whether he or she meets the SSI economic needs test. Under the current test of economic need, a child in a family of four begins to have his benefits reduced once the family's annual income reaches $8,484.00. When the family's income reaches $10,861.00 annually, the child is no longer eligible for SSI payments.

As a consequence of this so-called deeming process, a child living with his parents may be found to be ineligible for SSI payments or suffer a sharp reduction in his level of benefits. However, if the same applicant were living outside his parents' home, he normally would be considered on the basis of his own income and resources and, thus, would be entitled to receive SSI benefits. For example, in most instances, a child living in a licensed foster home or private institution is entitled to receive full federal benefits (i.e., $177.80 a month) while a child "living in the household of another" retains two-thirds of his SSI payment.

Raising a disabled child is a significant economic burden to all but the very wealthiest families in our society. Certainly the current economic means test used in the SSI program is so restrictive that many low and middle income families are faced with the heartrending choice of either placing their child in an out-of-home facility so he can qualify for benefits or forgoing badly needed federal/state assistance so the child can remain at home. However, while some liberalization of the economic means test seems warranted in the case of such families, elimination of the deeming requirement does not appear justified. Parents of handicapped children, like all other parents in our society, have a responsibility to participate in the cost of raising their offspring. The precise formula for distributing the costs of raising a handicapped child between the family and society is a subject which deserves detailed analysis; however, the basic principle which should be observed is that no family should be asked to assume more than the costs associated with rearing a normal child in today's society. Otherwise, distortions and inequities in public policy are likely to be perpetuated.

4. THE ONE-THIRD REDUCTION RULE. The present law stipulates that the benefits of any SSI recipient "living in the household of another" must be reduced by one-third if the aged, blind or disabled individual receives in-kind support or maintenance. By including this provision in the original legislation, Congress hoped to accomplish two objectives: (a) to take into account the fact that a person living with a friend or relative often has reduced living expenses; and (b) to simplify the process of determining the value of the in-kind support and maintenance furnished in such situations by assigning a fixed value of one-third of the current federal payment standard.

Instead of simplifying administration of the program, however, the one-third reduction rule has made it even more complex. Because the amount of in-kind support varies according to the type of living arrangement, SSA, in an attempt to apply the rule equitably, has been forced to develop complicated policies governing when it should and should not be used. For example, SSA has ruled that the one-third reduction does not apply if the recipient is contributing his pro rata share of household expenses. However, paying the pro rata share or current market value may not be a viable option since the SSI benefit levels are low and do not afford an individual the financial resources necessary to make substantial contributions to household expenses except where the household is functioning at a marginal income level. The one-third reduction also does not apply in situations in which an individual can show ownership interest or rental liability for the home in which he lives, or if the

recipient is living with other persons all of whom are receiving public assistance.*

By establishing such involved policies, the staff of the Senate Finance Committee believes that the Social Security Administration has added to the complexity of the program and overstepped the original intent of Congress. Their report points out that:

> "In the staff's interviews with field personnel, the one-third reduction was the most frequently cited policy area in which clarification or change was considered desirable. In its telephone survey of district office personnel the staff asked claims representatives in several offices to explain the workings of the one-third reduction provision and to cite the most important factor in determining whether or not it was applicable in a given case. The responses to this request indicated a great disparity of interpretation from office to office and from individual to individual. Many Social Security employees expressed the opinion that it would be an administrative simplification to simply drop the one-third rule and require them to determine the value of support and maintenance in-kind in every case. In fact, it seems that some claims representatives are applying the rule by first determining the value of support and maintenance in-kind, then determining the impact of the one-third reduction, and giving the claimant whichever of the two is more favorable to him. Such a procedure, of course, negates the intended effect of administrative simplification.[16]

Based on its review, the Finance Committee's staff concluded that the one-third reduction should be applied in all cases where a recipient is living in another person's household, "unless he can establish that the actual value of the in-kind support received is of lesser value."[16] Many other knowledgeable experts, however, feel the statutory provision authorizing the one-third reduction should be repealed. For example, the SSI Study Group, which reported to the Secretary of Health, Education, and Welfare in January, 1976, recommended the elimination of the one-third reduction rule. In explaining its reasons for making this recommendation, the Study Group noted that "a uniform payment level is desirable for administrative purposes and to minimize constraints on recipients' freedom of choice. Variations in payment levels by living arrangements reflect the objective of the former public assistance program to tailor assistance to individual circumstances. This is contrary to the principle of a uniform benefit level."[12]

Similarly, in its recent testimony on welfare reform, the National Association for Retarded Citizens contended that the one-third reduction rule limits the recipient's freedom to choose the most appropriate living situation. Speaking on behalf of the Association, Dr. Elizabeth M. Boggs noted that:

> "The federal income policy should strengthen incentives to families and other non-related individuals to care for an aged or disabled person within their home. It should facilitate the ability of the aged or disabled recipient to maintain himself in a non-institutional setting by affording him sufficient resources to contribute meaningfully towards his support in such settings. It should not create a situation in which a socially vulnerable and dependent recipient is encouraged to live alone in order to maximize his clearly meager cash benefit".[2]

She went on to point out that "in the case of families who have borne the extraordinary costs (social and emotional, as well as financial) of raising a severely disabled child, the prospect of unrelieved responsibility for basic support and maintenance during the adulthood of the disabled offspring, is particularly burdensome."[2]

Recommendation: Congress should repeal Section 1612(a)(2)(A)(i) of the Social Security Act which mandates a one-third reduction in federal payments to any recipient living in the household of another.

5. STUDENT STATUS. The payment status of SSI recipients between the ages of 18 and 21, living with their parents is confusing and inequitable. In general, such a recipient is considered to be a child if he is a full-time student enrolled in an accredited educational program. If, on the other hand, an individual in this age range is not a full-time student, he is considered an adult for payment purposes and parental income is not deemed to be available to him. However, the one-third reduction rule will be applied if he is living with his parents, a friend or relative who furnishes him with in-kind support and maintenance. In practice, it has proven to be extraordinarily difficult to determine whether a recipient meets the regulatory definition of a full-time student,

*For purposes of this provision SSA has defined public assistance to include Title IVA (AFDC), Title XVI (SSI), general assistance provided by the Bureau of Indian Affairs or state or local governments, and aid furnished under the Disaster Relief Act of 1974, the Migration and Refugee Assistance Act of 1962, and the Indo-China Migration and Refugee Assistance Act of 1975.

given the various types of educational and occupational training courses in which a blind or disabled recipient may be enrolled. In cases where the designation of "student" may jeopardize the individual's entitlement to SSI benefits, the current statutory provision serves as a disincentive to pursuing education and training which may assist the recipient to overcome or minimize the impact of his disabilities.

Recommendation: Congress should enact legislation to lower the statutory age of majority from 21 to 18. Such legislation has already passed the House of Representatives (Section 102, H.R. 7200) but, thus far, has not been approved by the Senate.

6. LIVING ALONE VS. MARRIAGE. Two aged, blind or disabled recipients can live together and both receive full SSI benefits, but the law requires that their payments be reduced if they marry. The total annual benefit for a single recipient is currently $2,133.60. Couples receive $3,200.40. This means two single disabled individuals living together would receive a total of $4,267.20. Should these two persons decide to marry, however, they would be treated as a single unit and suffer a reduction of $1,066.80 in benefits.

In a study dated May, 1976, the SSA Office of Research and Statistics found that there were 465,000 couples on the SSI rolls. It was estimated that it would cost the federal government an additional $250 million during fiscal year 1977 to treat all married couples as two individual recipients for payment purposes. However, the staff of the Senate Finance Committee in its recent report suggested that there has been "very little detailed analysis . . . of the various changes which could be made to simplify the program," citing the differential payment levels between single recipients and married couples as one obvious area of administrative complexity. The report went on to state that there appears to be a rather small proportion of couples receiving benefits—about 300,000 out of a caseload exceeding 4 million.[16]

Recommendation: Married couples, both of whom are entitled to SSI benefits, should be treated as two eligible individuals for payment purposes.

7. PAYMENTS TO INSTITUTIONALIZED INDIVIDUALS. Individuals residing in institutions may receive their full SSI benefit or find their monthly payment reduced by one-third, cut to $25 per month, or eliminated entirely depending on the type of institution in which they are living. This practice of varying payment levels according to the type of institution penalizes disabled individuals who happen to be living in the "wrong" kind of institution.

An institution is defined in SSA regulations as "an establishment which furnishes food and shelter to four or more persons unrelated to the proprietor and, in addition, provides some treatment or services which meet some need beyond the basic provision of food and shelter."[8] A facility is deemed to be a public institution when it meets the definition of an institution and is either operated by, or under the administrative control of a governmental unit. By law, an individual is ineligible to receive SSI payments for any month in which he resides in a public institution (Sec. 1611(e)(1)(A) of the Act). However, there are two exceptions to this general prohibition against payments on behalf of residents in public institutions. First, eligible residents in public medical facilities are entitled to receive a reduced payment of $25 a month. Second, publicly operated community facilities, serving 16 or fewer residents, are not considered to be public institutions and, therefore, otherwise eligible residents are entitled to receive SSI benefits.

SSI payments to an individual residing in any facility (public or private) which receives, or expects to receive, substantial Medicaid or Medicare payments on his behalf is entitled to receive $25 for each full month of institutionalization. This reduction in payment begins after the recipient has been in the facility for one month. "Substantial" Medicaid or Medicare payments has been interpreted by SSA to mean that over 50 percent of the cost of services are met through this source.

When an otherwise eligible individual is residing in a privately-operated, non-medical facility, he is entitled to receive full SSI benefits despite the intensity and range of services provided by the facility. However, the recipient's SSI benefit may be reduced if the facility in which he resides receives payments from third party sources other than private non-profit organizations. In such instances, the individual is considered to be receiving unearned income, and his SSI payment is reduced according to the presumed maximum value of the in-kind support and maintenance provided by the facility. The presumed maximum value in this situation is defined by SSA to be equivalent to one-third of the applicable standard payment amount plus $20.

Given these arbitrary distinctions between public and private, medical and non-medical facilities, it is not surprising that current statutory and regulatory policies

often tend to work at cross purposes with the Nation's goals for the developmentally disabled population. Indeed, it is difficult for states to develop sound deinstitutionalization strategies for disabled children and adults without clear and consistent policies on payments to recipients in institutional and non-institutional settings.

One approach would be to repeal the existing statutory prohibition against payments to otherwise eligible individuals in public institutions. A portion of the individual's SSI payment could then be applied to institutional costs which would reduce the burden on families or government entities who were previously paying these expenses. A report by the HEW Study Group[12] estimated the net additional SSI costs resulting from such a change in the law would amount to $300 million annually. These increased costs would result from a rise in the number of eligible SSI recipients and an increase in SSI administrative expenses. However, in the cases of Medicaid-eligible institutions, these increased costs presumably would be offset, at least in part, by a reduction in state and federal Medicaid outlays.

Any attempt to repeal the prohibition against payments to residents in public institutions, however, is likely to run into significant Congressional opposition. For example, commenting on this proposal in its recent report, the staff of the Senate Finance Committee said that implementation would represent:

> "a very major change of direction in public policy with respect to the funding of institutional care. It would, to begin with, involve a significant shift in the source of funding since care which is now being wholly provided for through private sources or through the Federal-State shared Medicaid program would, to the extent of the basic SSI payment level, become a wholly Federal responsibility. The question involved, moreover, is not simply one of fiscal liability. Where Congress has intentionally provided substantial Federal funding to underwrite institutional care it has done so through administrative mechanisms which can assure that reasonable value is being received for the money expended and that the necessary standards are enforced to protect the institutionalized population who tend to be particularly vulnerable. There is no reason to believe that Congress would want to reverse this policy."[16]

In any event, resolution of current deficiencies in financing care for individuals in institutional settings would require more than changes in SSI policies. In fact, it would be foolish to alter the provision of Title XVI without carefully considering the impact of such changes on other federal programs for financing long term care for elderly and disabled persons.

Recommendation: Congress should conduct an indepth analysis of present federal policies for financing long term care for the disabled. Included in this review should be an examination of the ways in which Medicaid, Medicare, SSI, Social Security and Social Services payments interact to provide incentives and disincentives to long term institutionalization.

An additional problem associated with SSI payments to persons in private non-medical institutions is that there is no requirement that funds be set aside for the recipient's personal needs. As a result, private non-medical institutions, unlike public and private medical facilities, are free to absorb the entire SSI payment for room, board and other expenses.

Recommendation: All SSI recipients residing in institutional settings—both public and private, medical and non-medical—should be entitled to receive a monthly personal needs allowance at least equal to the current payment to recipients in Medicaid eligible facilities (presently $25 per month).

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CHAPTER VII

THE ROLE AND FUNCTIONS OF THE REPRESENTATIVE PAYEE

Section 205(j) of the Social Security Act gives the Social Security Administration the responsibility to decide whether to pay benefits directly to a beneficiary or to someone else on his behalf. Representative payment is the means by which SSA seeks to protect the interests of those Social Security and SSI beneficiaries who are unable to protect their own interests.

Currently, SSA reports that approximately 6 1/2 million SSI and SSDI recipients have representative payees. The majority of such recipients are children. As of 1973, 1.6 million adults were under representative payment, of whom 268,000 were adults disabled in childhood.[2] Public mental institutions, or the central state agencies which operate such institutions, presently receive $140 million annually in benefit payments on behalf of the 132,000 residents under representative payment. Thus, it can be seen that SSA's representative payment program has a considerable impact on the lives of thousands of disabled SSI and SSDI recipients.

1. DETERMINATION OF INCAPABILITY.[3] The determination that an individual is not capable of managing his own benefits is separate and distinct from all other determinations, such as legal incompetence or commitment to an institution. A presumption of capability is applied to every case, regardless of an individual's status under guardianship or his living arrangement. Although a judicial finding of incompetence or a commitment to an institution constitutes strong evidence that a beneficiary needs a representative payee, it is not sufficient evidence standing alone. In cases where SSA believes that the interest of the beneficiary will be served, representative payment may be arranged even though there is no judicial finding of incompetence or commitment to a care institution. Similarly, direct payment may be made despite a finding of incompetence or commitment to an institutional facility.

A beneficiary is judged incapable only if evidence supports the presence of a mental or physical impairment and an inability to manage benefits. The individual's inability to manage his funds must be the result of the impairment. When an individual spends his money unwisely or injudiciously, this is not, in itself, a sufficient basis for depriving him of control over his benefits.

The following is a summary of the conditions which are sufficient evidence of the need for representative payment:

- The individual has deemed himself unfit to manage his property and his holdings have been placed under voluntary conservatorship.
- The individual's IQ is below 49 or mental age below seven.
- The individual is under 18 years of age.

In the absence of any of the above findings, certain medical, legal and other evidence is required:

- A physician's statement that the individual is incapable; or
- A court order showing that the individual is legally incompetent; or, if (1) or (2) are not available or are judged to be insufficient.
- The statement of a social agency, professional person, or family members.

Advanced notice of the proposed determination of incapability, including an indication of appeal rights, is sent to the beneficiary, and 15 days are allowed for protesting the decision before the action is final. The final determination can be appealed by the beneficiary unless he has been declared legally incompetent or is a minor. Where a beneficiary has been adjudged incompetent, the notice is sent to his or her legal representative, provided such individual is not considered likely to be selected as the payee. In the case of a minor, the advance notice is mailed to the parent, guardian or a person standing in place of the parent (e.g., a legal representative), provided that individual is not being selected as the payee. These latter individuals also may appeal the determination of incapacity.

2. THE SELECTION OF A REPRESENTATIVE PAYEE. The person (or appropriate public or private agency) designated to receive and disburse benefits on behalf of an entitled individual is called a representative payee. In many respects his duties and responsibilities are

similar to those which a court appointed legal guardian of the estate and of the person exercises with respect to his ward.

SSA has developed "preference lists" of possible payees. These lists are based on the criteria that the payee should be:

- A person who normally has responsibility for the individual;
- A person who has demonstrated a continuing concern for the individual and will continue to do so;
- A person who has demonstrated the ability to recognize the individual's needs and to plan for meeting those needs, as evidenced by past financial support, visits, gifts, letters, etc.;
- A person who is geographically close to the individual, and will continue to be close.

Applying these criteria, SSA has developed the following "preference lists" of possible payees (listed in priority order):

Adults:
(1) Legal guardian (but not statutory guardian), spouse, other relative. (N.B., a statutory guardian may be considered, but has a lower preference.)
(2) Friend with custody, or who displays a strong interest.
(3) Public or non-profit agency or institution having actual custody.
(4) Private institution operated for profit having custody and licensed by the state.

Children:
(1) Natural or adoptive parent with custody.
(2) Natural or adoptive parent not having custody but contributing to the beneficiary's support and demonstrating strong concern.
(3) Natural or adoptive parent not having custody, not contributing, but demonstrating concern for the child's well-being.
(4) Relative with custody.
(5) Relative not having custody but contributing and demonstrating strong concern.
(6) Legal guardian demonstrating strong concern for the child's well-being.
(7) Authorized social agency, authorized institution, or foster parent having custody.
(8) Relative or close friend demonstrating strong concern for the child's well-being.
(9) Legal guardian whose concern is mainly fiscal.

SSA is presently considering revisions to the preference list for children so that it will more closely parallel the list for adults.

Advance notice of the identity of the prospective payee must be given to the beneficiary. The selection of a representative payee is appealable, without exception.[5], [6], [7]

3. PREFERENTIAL SELECTION OF INSTITUTIONS OVER RELATIVES. In spite of policies which strongly favor the designation of non-institutional payees, there is evidence indicating that a public institution is often selected to serve as payee rather than a beneficiary's relative. In 1972, for example, public institutions served as representative payees for approximately 87,000 beneficiaries under their care. Yet, of these beneficiaries, SSA found that 43 percent had interested relatives or friends, as measured in terms of visits or personal mail received by the beneficiary.[9] While such indicators of "interest" must be viewed with caution, it would appear that factors favoring the selection of an institutional payee are at work in many cases.

SSA maintains that a primary goal of the representative payee program is to strengthen family ties. This goal would be especially important in those cases where the beneficiary is separated from the family and placed in an institution. But SSA reports that the identification and selection of parents or other advocates as representative payees is hampered by the following factors:

- A history of parents and relatives who have used beneficiaries' funds in questionable ways.
- Administrative efficiency and ease of monitoring. There is considerable pressure on the district office to move claims rapidly. Institutional payees are easier to find and to monitor.
- Nominal involvement of relatives who are payees in cases where the institution essentially directs the relative's use of benefits.

The existence of real barriers to the identification of non-institutional representative payees is borne out by the fact that institutional officials serve as representative payees in over one-half of the cases where Title II beneficiaries under representative payment are residing in public mental institutions.[18]

Recommendation: SSA should strengthen its efforts to identify and recruit non-institutional representative payees, such as parents, guardians, friends, advocates.*

*HSRI will identify obstacles to the designation of parents, guardians or friends as representative payees for SSI and SSDI recipients living in institutional settings during the course of a follow-up contractual study.

This should include exploring such possibilities as providing financial compensation to representative payees, publishing detailed instructions about rights and responsibilities, and utilizing the services of Protection and Advocacy agencies for developmentally disabled individuals established in accordance with Section 113 of P.L. 94-103.

4. DUTIES OF THE REPRESENTATIVE PAYEE. The Social Security Administration has developed detailed instructions for representative payees. These instructions spell out the payee's duties and responsibilities.[17]

Payment of benefits to a representative payee on behalf of a beneficiary creates a relationship which is analogous to a trust. The payee, like a trustee, must use his discretion in making proper disbursements of funds. No portion of the beneficiary's payment, however, may be withheld by the payee for services rendered, except as reimbursement for out-of-pocket expenses and, in the case of a legal guardian, for court fees. Potential remedies for misuse of the beneficiary's funds include change of payee, restitution, a civil suit, and criminal prosecution under Section 208(e) of the Social Security Act.

Use of Benefits: Payments made to a representative payee must be applied only for the "use and benefit" of the beneficiary. The payment is used in the beneficiary's interest if the expenditure secures some advantage or satisfaction for him. Prime factors to be considered when allocating funds on behalf of an institutionalized beneficiary are whether the expenditure will facilitate the earliest possible rehabilitation or release from an institution, or otherwise help the beneficiary live as normal a life as possible within the institution.

Disbursement for Current Support and Maintenance: Title II and Title XVI benefits are intended to be used for current maintenance expenses. Expenditures for current maintenance include food, clothing, shelter and other normal day-to-day living expenses. When a beneficiary is in an institution (except as a Medicaid eligible recipient in a Title XIX certified facility), SSA urges the representative payee to give highest priority to using benefits to pay the customary charges for institutional care.

Disbursements for Personal Needs. A portion of Title II and Title XVI benefits are intended for personal need items. Personal need items include clothing, transportation, toilet articles, and other commissary articles. When a Title XVI recipient is in a Title XIX facility and receiving a $25 monthly benefit, that payment must be used for personal need items rather than support and maintenance.

From time to time, SSA has authorized group purchases of items for the general use of contributing beneficiaries. In all cases, however: (a) other personal needs must be met first; (b) there must be conserved funds which can be used; (c) the item to be purchased must be an item which the institution normally does not provide; and (d) the group purchase must be authorized in advance by SSA.

Support of Dependents: Title II benefits may be used to support a wife, child, or other person who is a dependent. Title XVI benefits cannot be used for support of any dependent.

Savings: Title II benefits may be placed in a savings account or invested in U. S. Savings Bonds. However, SSA discourages the accumulation of Title XVI benefits; in fact, SSA reviews all cases where the recipient has accumulated more than $300.00 and savings in excess of $1,500 results in loss of benefits.

5. POST-SELECTION POLICIES. SSA has established post-selection procedures to determine if the representative payee is using payments made on behalf of a beneficiary in accordance with the law. Procedures include requiring representative payees to submit periodic written reports accounting for funds, making periodic contact with payees and custodians, and pursuing indications that such funds have not been applied for the use and benefit of the recipient.

Periodic reporting requirements have been expanded under SSA's "accountability program." All categories of payees, except spouses and parents with custody of minor beneficiaries, are now required to report how the beneficiaries' funds have been used. Accounting is done in one of two ways: by filling out a Representative Payee Report, or by on-site review. The report includes information about the beneficiary's place(s) of residence during the reporting period and about how the payee found out what the beneficiary's needs were. The form also requires a detailed reporting of the beneficiary's income and expenditures.[10, 11, 12, 13] In cases of payees who do not have custody of the beneficiary, SSA asks the custodian institution to verify all reports of payment for current support and maintenance. This verification program has been implemented for some categories of Title II beneficiaries, and is planned for Title XVI recipients as well.

6. THE PERFORMANCE OF INSTITUTIONAL PAYEES. Prior to 1970 public institutional payees submitted written accounting reports on each recipient. In 1969 alone, about 100,000 reports on beneficiaries under institutional representative payment were processed by SSA. The time and cost of gathering and reviewing these reports became so prohibitive that SSA concluded that individual reporting was not a satisfactory approach to evaluating the overall performance of public institutions serving as payees for large numbers of beneficiaries.[8] As a partial solution, SSA established the Representative Payee Onsite Review program in 1970. The purpose of this program was to evaluate the payee performance of state institutions. Since 1970, these reviews have been conducted biennially in all 50 states and the District of Columbia.

At present, the onsite review program is conducted only in public institutions. A recent analysis of Title II beneficiaries under representative payment, however, shows that the number in proprietary institutions has increased from 124,000 in 1969 to 176,000 in 1973 while the number in public mental institutions dropped from 170,000 in 1973 to 138,000 in 1973. The author of the study hypothesizes that "some of the change may be attributable . . . to shifts out of the former type of institution into the latter."[2]

Under the circumstances, as a matter of public policy, it is difficult to justify applying the onsite review program in public institutions and not in private non-profit and proprietary institutions, especially in view of the findings of a recent General Accounting Office study which documents the inadequate control of patients' personal funds in Medicaid-eligible skilled nursing and intermediate care facilities.

GAO reported that many of the same inadequacies found by SSA onsite review teams in public institutions were also evident in the 18 proprietary nursing homes, seven public and five non-profit facilities reviewed. Some of the major deficiencies uncovered were:

- Inconsistencies between the patients' bank accounts and the facilities' ledger balance;
- Charging patients for medical services and supplies;
- Retaining personal funds of deceased and transferred patients;
- Keeping interest earned on patients' funds.

In addition, some facilities were found to be mingling patient funds with those of the institution and using such funds to cover operating expenses. Poor procedures for documenting patient fund transactions and failure to provide quarterly statements of patients' accounts were also uncovered in the course of GAO's study.[18]

Recommendation: SSA's on-site review program should be extended to private non-profit and proprietary facilities acting as representative payees for Title II and Title XVI beneficiaries.

In carrying out onsite reviews, SSA representatives visit state institutions where they meet with officials to obtain information relating to the policies and operating procedures of the particular facility. The teams also gather specific information concerning a preselected, random sample of beneficiaries under representative payment to the institutions. The onsite review includes examination of fiscal records for the previous 12 months, interviews with ward personnel knowledgeable about each beneficiary, and where possible, a brief visit with each beneficiary in the sample.

The stated objectives of the onsite review are: (a) to explore ways in which SSA and the institutions can work toward the resolution of common problems; (b) to ascertain whether the state institution performance as payee is in conformance with SSA policies regarding use of benefits and reporting of significant events; (c) to determine the extent to which recommendations made in prior cycles have been carried out; and (d) to take appropriate action to assure compliance with SSA policies. The most recent analysis of onsite review reports completed by SSA was issued in 1973. It was based on the findings from visits made in 1970 and 1971.[9] This summary report identified the following areas in which institutions tended to function inadequately.

Personal Spending: When benefits are paid to an institutional superintendent as representative payee, it is with the understanding that funds will be used to pay for the needs of the individual beneficiary. The 1973 report indicated that institutions do not always carry out this responsibility. Onsite review teams found the following common abuses:

- Administrative and ward staff were uninformed about the proper uses of Social Security benefits.
- Ward personnel were unaware that residents had funds available.
- Residents who were incapacitated and unable to express their needs often received little or nothing in the way of personal items.
- Basic personal needs were unmet. The 1973 report showed that 47% of all beneficiaries had no record of

expenditures for clothing, and that over 4,700 beneficiaries had no personal expenditure whatsoever during the 12 month review period.

- Proceeds from large retroactive checks were sometimes used to defray past support charges instead of current and foreseeable needs, as required by SSA regulations.

Group Purchases. Onsite review teams reported some misunderstanding of SSA policy on individual contributions to group purchases. For example, the report cited several instances in which equipment the state would normally be expected to provide was purchased with residents' funds.

Reporting Responsibilities. Reports on a clients' eligibility for benefits, according to onsite review teams, were often inaccurate and delayed. For those residents no longer residing in the institution but still under representative payment to the institution (16% of all recipients in the 1973 review), the reporting problem was compounded. Accuracy and timeliness of information was adversely affected.

Payment for Care and Maintenance. The 1970-71 onsite review teams found that methods of determining the actual amount to assess a beneficiary for care and maintenance varied from one state to another, and often among institutions within the same state. Some institutions related income to care and maintenance charges so that all residents whose income fell within a given range were assessed for care and maintenance. This "means" test sometimes related to the total family income, in other instances only to the resident's income. Another payment procedure involved allocating a fixed amount for personal use with the balance of income applied toward care and maintenance. This fixed amount was usually established either by institutional or state policy. A rare variation of this practice was an attempt to set aside personal funds according to the needs of individual beneficiaries with the balance for care and maintenance. There were also states in which none of these practices appeared to be applied and care and maintenance assessments seemed to follow no discernible pattern. In nearly all jurisdictions the determination as to care and maintenance charges were made solely by fiscal staff who had little knowledge of a resident's current or future need for personal spending funds.

Update of Onsite Reports. Earlier it was noted that SSA had not summarized the results of onsite review reports since the completion of the first cycle of visits in 1970-71. In order to obtain more timely data, the NASMRPD project staff recently reviewed the summary reports from the third cycle of onsite reviews (1975-1977) in ten states.[3] The findings of this analysis indicate that there has been some improvement in the performance of institutional representative payees. Institutions appear to be doing a better job of meeting current maintenance needs before using benefits for other purposes; maintaining complete, accurate and current records of the patients' financial situation; and reporting on a timely basis all changes affecting benefit payments. However, institutional performance continues to be deficient in the following areas:

- Personal needs expenditures remain low in some states and do not appear to be related to the specific needs of the individual.
- Benefits which are allocated for personal needs are sometimes diverted to care and maintenance charges because personal savings have reached an arbitrary ceiling imposed on the accumulation of personal funds.
- Some institutions remain payee for individuals who have been released from the institution for substantial periods of time.

Recommendation: The Social Security Administration should provide policy and procedural guidelines for individuals and institutions that serve as representative payees. The guidelines for institutions should contain suggested methods of accounting for residents' funds, informing the staff about funds available to residents, and methods for reaching decisions about expenditures for care and maintenance, personal needs and savings.*

Recommendation: The Commissioner of Social Security should appoint a joint study group made up of regional and district office staff with responsibility for onsite reviews, and public and private institutional officials who serve as representative payees, to identify ways of improving the quality of information generated through the onsite review process and thereby to increase the usefulness and accuracy of these reports to SSA, the institution, the beneficiary and client advocacy agencies.

7. THE PERFORMANCE OF NON-INSTITUTIONAL REPRESENTATIVE PAYEES. In March, 1976, the Attorneys General of Massachusetts and Connecti-

*The project staff is currently in the process of developing a set of recommended guidelines for institutional payees in cooperation with a board of advisors made up of selected members of the National Association of State Mental Retardation Program Directors, Inc., the National Association of Superintendents of Public Residential Facilities for the Mentally Retarded, Inc., the National Association of Private Residential Facilities for the Mentally Retarded, Inc., and the National Association of Reimbursement Officers.

cut petitioned HEW to revise its existing rules governing the selection and monitoring of representative payees for Title II and Title XVI beneficiaries.[1] The petitioners argued that recipients are denied due process of law since the current regulations lack provisions for adequate notice, an opportunity for a prior hearing, clear selection criteria, and evidence that appointments are based on factual findings. Changes proposed in the regulations included a requirement that the need for a representative payee be more closely examined and that a specific factual finding of fiscal incompetency be made before a beneficiary was placed under representative payment.

Calling SSA's supervision of representative payees generally "lax to nonexistent," the petitioners demanded that responsible institutional officials be required to sign an agreement specifying that the recipient's money would be spent in accordance with a predetermined plan and an annual accounting of expenditures would be rendered to SSA. When an individual payee was designated to handle the funds of an institutionalized recipient, the petitioners asked that failure to pay for the recipient's care, maintenance and rehabilitation be considered grounds for automatic removal of the payee. In addition, the Massachusetts and Connecticut Attorneys General suggested that the person having actual custody of the recipient be granted access to the accounting forms filed by the payee.

To protect against stolen or misused funds, the petitioners suggested that a representative payee be required to post a surety bond. The amount of the bond would be equal to the value of the accumulated estate derived from Title II or Title XVI benefits plus the total amount of the payments for a given accounting period. SSA attorneys would also be authorized to make appearances in state courts to file petitions for the appointment and removal of guardians, to take legal actions for recovery of improperly handled funds, etc.

The Massachusetts/Connecticut petition was based in part on "more than 100 documented cases" of individuals whose SSA benefits had been improperly diverted to third persons who were functioning as representative payees. The GAO, in a follow-up action, is reportedly investigating 33 of the cases cited in the petition. The results of this investigation were not available at the time of this writing.

In April, 1977, the Social Security Administration responded by letter to the Massachusetts/Connecticut petition.[4] SSA stated that the beneficiary has the right to appeal both the capability and selection decisions. In addition, all legally competent adult beneficiaries and recipients have the right to appeal the capability determination. Further, the right to appeal the payee selection is granted to all beneficiaries. Notice of the proposed decision is sent to the beneficiary before the change is made, and ten days are allowed for protesting the decision before any change is finalized.

Related to the supervision issue, the SSA response pointed to recent improvements in the onsite review process, and said,

> "Unfortunately, most institutions realize that they have been selected as payees because no other preferable payee is available, and that even if the Social Security Administration is dissatisfied with their performance, there is frequently no recourse but to continue payment to them. The Social Security Administration is currently attempting to develop some means of locating and making payment to alternative payees where institutions or other payees are performing unsatisfactorily."

Finally, the SSA response noted that SSA has the authority to appear in court to recover funds improperly used "and does now exercise this authority."

Recommendation: SSA's auditing and reporting responsibilities as they affect non-institutional representative payees should be strengthened.

REFERENCES — CHAPTER VII

THE ROLE AND FUNCTIONS OF THE REPRESENTATIVE PAYEE

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9. Social Security Administration. **Onsite review of state mental institution performance as representative payee** (SSA Publication 60-73). Baltimore, Maryland: August, 1973.

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11. Social Security Administration. "Representative payee onsite review program beneficiary information report" (Form SSA-9585). Baltimore, Maryland: August, 1975.

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APPENDIX A

SSI Payment Levels for Disabled Persons by State and by Living Arrangement July, 1976

State and Living Arrangements	Payments Levels for - Individuals	Couples
Alabama:		
Living independently	$ 167.80	$ 251.80
In personal or foster care home	167.80	308.00
In nursing home or TB sanitarium:		
(1) Eligible for SSI	25.00	50.00
(2) Public and no medicaid payment	22.00	44.00
Living in cerebral palsy treatment center	377.00	754.00
Alaska:		
Living independently and actual shelter costs less than $35	270.00	405.00
Living independently and actual shelter costs is $35 or more	334.00	490.00
Arizona:		
Living independently	167.80	251.80
In licensed private nursing home	238.00	397.00
In licensed county-operated nursing home	174.00	348.00
Arkansas: Living Independently	167.80	251.80
California:		
Independent living with cooking facilities	276.00	522.00
Out of home care	323.00	646.00
Independent living without cooking facilities	308.00	586.00
Living in household of another	220.07	438.07
Disabled minor in house of parent or relative	228.00	NA
Colorado: Living independently	185.00	370.00
Individual with essential spouse	258.00	NA
Home care	402.00	587.00
Connecticut: Living independently	256.00	312.00
Delaware:		
Adult foster home	255.00	510.00
Living independently	167.80	251.80

APPENDIX A (continued)

State and Living Arrangements	Payments Levels for - Individuals	Couples
District of Columbia:		
Adult foster care	$ 170.00	$ 340.00
Living independently	167.80	251.80
Florida:[2]		
Room and board with personal care	200.00	400.00
Adult foster care home	225.00	450.00
Living independently	167.80	251.80
Georgia: Living independently	167.80	251.80
Hawaii:		
Living independently	183.00	276.00
In household of another	115.00	178.00
Domiciliary Care I	258.00	516.00
Domiciliary Care II	308.00	616.00
Domiciliary Care III	370.00	740.00
Idaho:		
Living independently	231.00	302.00
In household of another	111.87	167.87
Eligible individual with essential person	302.00	NA
Converted case	302.00	——
Room and board	312.00	624.00
Hotel-Renting room	202.00	NA
Illinois: Living independently	175.00	251.80
Indiana: Living independently	167.80	251.80
Residential facility up to	492.80	NA
Iowa:		
Living independently	167.80	251.80
Household of another	111.87	167.87
Living with dependent person	251.80	335.80
Converted case with essential person	251.80	335.80
In family life home/boarding home	221.00	462.00
Kansas:		
Living independently	167.80	251.80
Converted case	203.00	------
Kentucky:		
Living in personal care facility (non-title XVI)	310.00	620.00
Family care home	248.00	496.00
Individual requiring a nurse in the home	206.00	285.00
Both requiring a nurse	NA	313.00
Living independently	167.80	251.80

APPENDIX A (continued)

State and Living Arrangements	Payments Levels for - Individuals	Couples
Louisiana: Living independently	$ 167.80	$ 251.80
Maine:		
Living independently	177.80	266.80
Living with others	175.80	263.80
In household of another	119.87	179.87
Foster or licensed boarding home (5 or less beds)	210.00	420.00
Licensed boarding home (more than 5 beds)	225.00	450.00
Maryland:		
In domiciliary care facility	250.00	500.00
Living independently	167.80	251.80
Massachusetts:		
Living independently	271.54	413.70
Shared living expenses	206.60	413.70
In household of another	189.54	331.58
Boarding home care	204.58	413.70
Domiciliary care	347.78	695.56
Michigan:		
Living independently	192.10	288.20
In household of another	128.07	192.10
Domiciliary care	265.10	530.20
Personal care	335.60	671.20
Home for aged	354.40	714.80
Independent living with essential person (converted case only)	276.10	372.20
In household of another with essential person (converted case only)	184.07	248.10
Minnesota: (Payment levels shown are for Hennepin County, Minneapolis)	196.00	289.00
Mississippi: Living independently	167.80	251.80
Missouri:		
Living independently	167.80	251.80
Licensed domiciliary nursing home[3]	317.80	551.80
Licensed practical or professional nursing home[3]	367.80	651.80
Montana:		
Adult foster care and boarding care	216.80	433.60
Licensed developmentally disabled home	271.80	543.60
Living independently	167.80	251.80

APPENDIX A (continued)

State and Living Arrangements	Payments Levels for - Individuals	Couples
Nebraska:		
Living independently[3]	$ 233.00	$ 326.00
Living with essential person[3]	326.00	NA
Room and board	209.50	419.00
Adult foster home[3]	219.50	439.00
Nevada:		
Living independently	202.75	323.00
In household of another	135.17	215.34
Domiciliary care	300.00	600.00
New Hampshire:		
Living independently	202.75	323.00
Individual or couple with essential person	235.00	300.00
Converted case	251.80	335.80
Living in shared home for adults:		
Family care	200.00	NA
Group home	240.00	NA
New Jersey:		
Licensed boarding house	298.00	596.00
Living independently or purchasing room and board	190.00	262.00
With ineligible spouse	262.00	NA
Living with 1 or 2 others:		
Own household	167.80	251.80
Household of another	133.00	236.00
Living with 3 or more others:		
Own household	167.80	251.80
Household of another	111.87	196.00
New Mexico:		
Living independently	167.80	251.80
Shelter care facilities/personal care services	187.80	291.80
New York:		
Living independently	228.65	327.74
Living with others	175.98	278.74
Congregate care I:		
Area A	291.70	583.40
Area B and C	236.70	473.40
Congregate care II	386.70	773.40
Congregate care III:		
Area A	650.70	1,301.40
Area B	626.70	1,253.40
Area C	311.70	623.40
In household of another	120.05	194.81

APPENDIX A (continued)

State and Living Arrangements	Payments Levels for - Individuals	Couples
North Carolina:		
Living independently	$ 167.80	$ 251.80
In domiciliary care:[4]		
Ambulatory individual	312.00	NA
Situation A	NA	427.00
Situation B	NA	389.00
Semiambulatory individual	322.00	NA
Situation A	NA	437.00
Situation B	NA	399.00
Nonambulatory individual	322.00	NA
Situation A	NA	447.00
Situation B	NA	409.00
Ineligible for SSI:		
Maintaining own home	115.00	NA
In multiple household	77.00	NA
With needy essential person in own home	150.00	NA
With needy essential person in multiple household	100.00	NA
North Dakota: Living independently	167.80	251.80
Ohio:		
Living independently	167.80	251.80
In mental retardation and developmentally disabled facility	260.80	NA
Oklahoma:		
Living independently	189.70	300.60
Living independently with meals at restaurant	204.70	330.60
In household of another	137.00	222.00
In nursing facility (monthly income $50 or less)	65.00	130.00
Oregon:		
Living independently	179.80	261.80
With an ineligible spouse or essential person	261.80	NA
In household of another	130.90	223.23
In adult or group foster care	179.80	359.60
In board and room	179.80	359.60

APPENDIX A (continued)

State and Living Arrangements	Payments Levels for - Individuals	Couples
Pennsylvania:[3]		
Living independently	200.20	300.50
In household of another	144.27	216.57
With 1 essential person (converted case)	300.50	408.86
With 1 essential person in household of another (converted case)	216.57	296.93
In foster care home for adults	315.10	625.20
Rhode Island:		
Living independently	199.24	311.12
In household of another	148.67	235.18
South Carolina:		
Living independently	167.80	251.80
In licensed boarding home	229.00	458.00
South Dakota:		
Living independently	$ 167.80	$251.80
Converted case	190.00	——
In supervised personal care[3]	255.00	510.00
In adult foster care home[3]	180.00	360.00
Tennessee: Living independently	167.80	251.80
Texas: Living independently	167.80	251.80
Utah:		
Living independently	167.80	251.80
In household of another	111.87	167.87
In licensed mental retardation center	311.70	——
Vermont:		
Living independently		
Area 1	200.00	295.00
Area 2	200.00	315.00
In household of another	135.00	198.00
Supervised licensed custodial care	286.00	525.00
Unlicensed home custodial care	228.00	444.00
Licensed home custodial care	253.00	494.00
Virginia:		
Living independently	167.80	251.80
In licensed home for the aged or domiciliary institutions	193.00 and up	386.00 and up

APPENDIX A (continued)

State and Living Arrangements	Payments Levels for - Individuals	Couples
Washington:		
Living independently:		
Area 1	201.90	287.80
Area 2	185.65	257.85
With ineligible spouse:		
Area 1	287.80	NA
Area 2	257.85	NA
With essential person (converted case);		
Area 1	287.80	NA
Area 2	257.85	NA
In household of another (Areas 1 and 2)	124.55	183.50
In household of another:		
With ineligible spouse (Areas 1 and 2)	183.50	NA
With essential person (converted case) (Areas 1 and 2)	183.50	NA
West Virginia: Living independently	167.80	251.80
Wisconsin:		
Living independently	234.00	351.00
In household of another	272.10	NA
In household of another with ineligible spouse	219.54	NA
Independent living with an essential person (converted case only)	318.00	435.00
Living in the household of another with an essential person (converted case only)	237.44	328.17
Independent living with ineligible spouse / essential person (converted case only)	356.10	NA
Living in household of another with ineligible spouse/essential person (converted case only)	275.54	NA
In private non-medical group home	350.00	700.00
Wyoming: Living independently	167.80	251.80

SOURCE: "The Supplemental Security Income Program", Staff report to the Committee on Finance, U.S. Senate, April, 1977.

REFERENCES - APPENDIX A

[1]The amount shown is the total amount payable in the specified circumstances to an individual or couple in combined Federal SSI payments and State supplementary payments for basic needs. In some cases, additional amounts are payable by the State for special needs. Individuals who were on the State welfare rolls in December 1973 may also in some instances receive additional amounts under the mandatory supplementation grandfather clause. See table 1 for information as to whether State supplementary payments are administered by the State or by the Federal Government. The Federal component of the payments shown are: Full benefits: $167.80 for individuals; $251.80 for couples; persons living in household of another: $111.87 for individuals: $167.87 for couples; individuals in medicaid institutions: $25.

[2]Optional State supplementation available only to individuals receiving some Federal SSI benefits.

[3]Maximum payment; may be less depending upon amount charged for rent or institutional care as applicable.

[4]Situation A: with spouse maintaining a home; situation B: with spouse living in multiple household.

APPENDIX B

EXCERPTS FROM LETTERS OF ENDORSEMENT

Epilepsy Foundation of America

"I would like to commend you on a thoughtful and well-written piece of work, and to endorse the project's recommendations.

As you know, the National Commission for the Control of Epilepsy and Its Consequences has recently released its report 'Plan for Nationwide Action on Epilepsy'. The Commission studied many of the same issues as 'Income Maintenance and the Developmentally Disabled'. I have included their recommendations dealing with these specific issues for your consideration and sharing with other members of the study group. While the Commission's recommendations are epilepsy-specific, the problems they address are endemic to the entire DD population."

William M. McLin, Director, Governmental
Liaison, Epilepsy Foundation of America
September 30, 1977

National Association of Private Residential Facilities For the Mentally Retarded, Inc.

"The National Association of Private Residential Facilities for the Mentally Retarded Legislative Committee has reviewed the recommendations of the NACSPMR Technical Assistance Project relative to Federal income maintenance programs and has agreed that NAPRFMR will support each of them.

Our Association is impressed with the thoroughness of this study and believes considerable material has been provided within the body of the document to support each of the recommendations. We are pleased to have this opportunity to contribute to national efforts to improve Federal programs which benefit Americans who are developmentally disabled. Be assured that NAPRFMR will work actively to achieve the changes you and your staff have suggested."

Joni Fritz, Executive Director
National Association of Private Residential
Facilities for the Mentally Retarded
November 3, 1977

National Society for Autistic Children, Inc.

"The National Society for Autistic Children is pleased to endorse the report, 'Income Maintenance and the Developmentally Disabled'.

We have no adverse comments and NSAC will lend its full support to implementation of the recommendations.

Richard S. Naceivicz, Chairman
National Affairs Committee, National
Society for Autistic Children
September 26, 1977

United Cerebral Palsy Associations, Inc.

"United Cerebral Palsy Associations, Inc. endorses the recommendations contained in the report **Income Maintenance and the Developmentally Disabled: An Analysis of Policy Issues.** We do believe certain policy areas are more important to persons with cerebral palsy than others; as such, we request that this endorsement letter be included in the final report. Additionally, we stress our priority concerns because of the cost of implementing recommendations at a time when the Social Security Trust System is experiencing financial difficulty.

UCPA believes the issues related to (1) eligibility for rehabilitation services, (2) incentives and disincentives to employment, and (3) relationship between living arrangements and benefit levels are priority areas requiring immediate attention. Their impact seems greater than those associated with disability determination (an area with few problems for persons with cerebral palsy) and representative payees (an area generally only applicable to persons with substantial mental impairments).

The report seems to reinforce the potential importance of State Protection and Advocacy Systems and thus we suggest that agencies primarily interested in P & A development also be recipients of the report.

We particularly endorse the recommendation that DHEW appoint a task force to address the issues of responsibility for implementation of individual plans. In addition to the requirements cited in the report, we call your attention to Section 141(b) of P.L. 93-380 which requires individual plans for all Title I ESEA children and Section 405.250(3) of the Medicare regulations which requires individual plans for all physical therapy and speech pathology services delivered under the program. . . .

UCPA also supports the long term care financing proposals. Several of our affiliates and affiliate staff such as physical and occupational therapists have experienced undue hardship in being denied classification as certified Medicaid providers. We encourage the report be distributed to professional societies experiencing Medicaid reimbursement difficulties. The differentiation between 'medical' and 'habilitation' outlook presents serious obstacles to utilizing Medicaid on behalf of persons with developmental disabilities.

Though we fully endorse the incentives and disincentives to employment recommendations and believe they are a priority concern, we must caution readers regarding sheltered workshop placements. The traditional vocational habilitation approach to persons with severe disabilities has been dominated by an expentancy cycle that perpetuates low levels of success and low employment capabilities. This approach has resulted in reliance on long term sheltered workshop placements emphasizing simple, menial task activity. Several UCPA affiliates have demonstrated that most severely physically disabled persons, with normal or near normal intelligence, can function in more competitive employment situations if task analysis, performance analysis, and applied technology is emphasized. We view sheltered workshop placement as transitionary and do not value them as true employment until workshop participants earn at least the minimum wage. The objective in improving sheltered workshop treatment of participants should always be to increase their ability to move toward more competitive work activity.

Lastly, we commend NACSPMR and specifically the project staff for the development of such a comprehensive, detailed and quality report. UCPA appreciates the fact that every suggestion made by Clarke Ross was carefully considered and incorporated into the report. We take pleasure in knowing that consumer, provider, and professional interest groups can effectively work together and reach concensus decisions. Let us demonstrate continued cooperation as we attempt to implement the report's recommendations."

Muriel Lee, Vice Chairman,
Governmental Activities Committee,
United Cerebral Palsy Associations
October 4, 1977

Elsie D. Helsel, Ph.D.
Chairperson
Governmental Activities
Committee
United Cerebral Palsy Associations

National Easter Seal Society for Crippled Children and Adults, Inc.

"In addressing the issues in the Report on Income Maintenance and the Developmentally Disabled, the Project Staff has presented an in depth analysis of the complex problems and factors involved. The resulting recommendations should aid greatly in providing for a more equitable program for disabled recipients. The National Easter Seal Society for Crippled Children and Adults is pleased to endorse the report.

You will be interested in action NESSCCA and other organizations have taken with regard to influencing policy and provisions in the pending Welfare Reform legislation.

On October 14 a panel of three persons, including Richard Verville representing NESSCCA, presented testimony on the Welfare Reform Bill on behalf of twelve organizations. I assume you have a copy of the written testimony, and believe you would like to read the oral statement of Richard Verville, and the questions submitted to him by the Committee members."

Rhoda Gellman, Director
External Affairs
National Easter Seal Society
for Crippled Children and Adults
November 7, 1977

National Association for Retarded Citizens, Inc.

"This letter is to convey the endorsement of the National Association for Retarded Citizens of the materials prepared on Income Maintenance and the Developmentally Disabled by the National Association of Coordinators of State Programs for Mentally Retarded Developmental Disabilities Project. I am well aware of the considerable effort that went into the development of the analysis document and the subsequent recommendations. The documents reflect current issues of great importance to NARC.

We look forward to a united and concerted effort to implement the recommendations."

Paul A. Marchand, Director
Governmental Affairs Office
National Association for
Retarded Citizens
December 29, 1977